

“Just one thing after another”

Living with multiple conditions

A report from the Taskforce
on Multiple Conditions

October 2018

The
Richmond
Group
of Charities



Royal College of
General Practitioners

Foreword

It's increasingly common that people affected by long-term health conditions will be living with several rather than just one, and yet their experiences often go unheard. Systems and services, across the public and voluntary sector, are largely geared around single diseases. This ethnographic research gives a voice to people living with multiple long-term conditions, uncovers the range of complex factors that impact their daily lives and helps us focus efforts on what matters.

There is a significant evidence gap around 'multimorbidity' (the term itself is alienating to those with multiple conditions). This research draws on a broad and diverse range of people in terms of income, place and age to understand their lived experience. Their stories illustrate that people's progression from one to many conditions varies significantly, influenced by both health and social factors.

It's striking that people didn't speak in terms of their individual diagnoses – they instead spoke movingly about the compound impact to their lives. We hear about missed opportunities to intervene; the series of losses – biomedical, relational or psychological – that add further complexity to ill health; and the accumulation of further illnesses. A better understanding of the journey and challenges people face helps us identify opportunities to act, and explore interventions and initiatives that could slow down progression, helping people live better for longer. Very small interventions can make a significant and positive difference to people's lives.

The Taskforce must not reinvent or duplicate good work and excellent initiatives already underway. Neither do we want to repeat arguments for single conditions that are also true for multiple conditions. We must ensure anything we do: builds on rather than replaces work already being done; addresses a need or aids transformation in the system; and offers meaningful support to people with multiple conditions.

For the Royal College of General Practitioners, as generalists, and as the first point of contact for patients, GPs are natural providers of person-centred holistic care. However, they face immense workload pressures as the demand for appointments and complexity of conditions grows. Supporting people with multiple conditions requires a multidisciplinary approach, where partnership with the voluntary sector is an imperative.

Guy's and St Thomas' Charity are focused on big health challenges that affect inner-city areas, such as multiple conditions. The point at which each person goes from one to many health conditions varies hugely but not randomly. Rather, it seems to track issues of deprivation, culture, lifestyle and place. By listening to the experiences of people like Paul, Megan and Godfrey from Lambeth, we can begin to understand much more clearly how and why.

The Richmond Group of Charities knows that many people who contact individual organisations seeking support with one condition are also living with other conditions and too often experience siloed, condition-based, care and support. We want to change this, in our own charities' practice as well as across the health and care system.

It is never too late to improve. This research contributes an essential and often unheard voice to an important national debate. In sharing it, we hope to encourage collective action to secure a better deal for people living with multiple conditions. It requires a profound shift in how we both think about and coordinate services around health. Focusing on individual diseases underplays the cumulative impact on individual health and wellbeing and the wider impact on individual's lives.

If we want to encourage people to be independent, they need to be able to depend on the system. If we can get this right for such a complex issue, we will be in a good place for caring for all those with long term conditions more generally.



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Introduction

As the NHS celebrates its 70th birthday, there is growing evidence and increasing recognition that our health and care system predominantly serves people living with multiple long term physical and mental health conditions. Earlier this year, we established the Taskforce on Multiple Conditions, a cross-sector partnership led by The Richmond Group of Charities, Guy's and St Thomas' Charity and The Royal College of General Practitioners.

The overarching aim of the Taskforce is for people with multiple long-term health conditions (MLTCs) to live as well as possible for as long as possible. We know that around 15 million people in England have a long-term condition, and the number of people living with several of these conditions is increasing in absolute terms and relative to single morbidity*. Unfortunately, we also know that our health and care system is, in most cases, not structured to deal with this growing challenge.

Evidence to date has focused on exploring clinical perspectives and interventions. But *what is it really like to live with several long-term conditions that can be managed but not cured?* We need to understand the lived experience of people with multiple conditions and the impact on their lives, in order to ensure our health and care system is supporting and enabling people to live as well as possible for as long as possible.

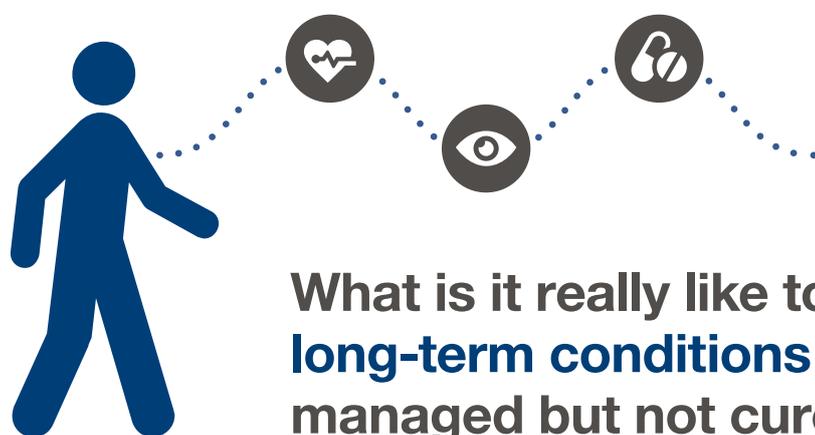
Today we publish our first research report, an ethnographic study of ten people each living with two or more long-term conditions. Participants were selected from across England and from a range of background demographics. In-depth, open-ended interviews were conducted in participants' homes, designed to understand peoples' everyday experiences and perceptions of their quality of life. By taking an ethnographic approach, we could take account of individuals' wider circumstances and ask what matters most to people when thinking about the provision of care and support.

A series of rich and complex portraits emerge, highlighting several common patterns and shared experiences. Inevitably, a small group of interviews can never tell us everything, and it is true that more questions are surfaced than answered here. But we hope that by giving voice to people living with multiple conditions we can begin to better understand how systems and services can be developed which are more responsive to people's own needs and wishes. Considering these thematically provides the link between the individual and the system – and paves the way for recommendations that are relevant to health and social care professionals in public and private settings, the voluntary and charity sectors, policymakers, advocates, carers and, of course, the people living with multiple health conditions themselves.

As we publish this research, we are aware of the forthcoming Long Term Plan for the NHS, the 2019 Budget and Comprehensive Spending Review and the Social Care Green paper. The insight from this research, as well as the areas set out for further thinking, should inform these plans.

Part one of this report sets out the ethnographic research by Revealing Reality.

Part two of this report sets out the response from the Taskforce on Multiple Conditions.



What is it really like to live with several long-term conditions that can be managed but not cured?

*Department of Health (2012). Report. *Long-term conditions compendium of Information: 3rd edition*

Part one

| | | | |
|----|---|----|--|
| 6 | Executive summary | 36 | Reducing the 'health bandwidth' |
| 8 | Introduction | 36 | Daily routine |
| 10 | Method | 37 | Work |
| 10 | Sample | 37 | Hobbies |
| 10 | Interview approach | 38 | Maintaining meaningful relationships |
| 10 | Analysis | 38 | Supporting independence |
| 12 | Chapter one: Living with multiple health conditions | 39 | Maintaining and expanding social networks |
| 12 | Anna, 24, Somerset | 39 | Developing productive relationships with professionals |
| 14 | Megan, 42, Lambeth | 40 | Building relationships |
| 16 | Wendy, 44, Wirral | 40 | Health and care hacks |
| 18 | Paul, 47, Lambeth | 41 | Investigative mindset |
| 20 | Susan, 53, Cambridgeshire | 42 | Chapter three: What support do people need? |
| 22 | Matilda, 55, Peak District | 43 | Promoting mobility |
| 24 | Vivienne, 55, Leeds | 43 | Personal, empowering support |
| 26 | Keith, 57, Northumberland | 44 | Recognising mental wellbeing |
| 28 | Godfrey, 71, Lambeth | 45 | Informal support to maintain quality of life |
| 30 | Peter, 81, Taunton | 45 | Working out what works |
| 33 | Chapter two: How do people adapt to life with multiple conditions? | 46 | Clarity on how to work with the system |
| 34 | Feeling in control | 48 | Chapter 4: Principles for a holistic approach |
| 34 | Self-management strategies | 51 | Conclusion |
| 35 | Directional approach to healthcare | | |

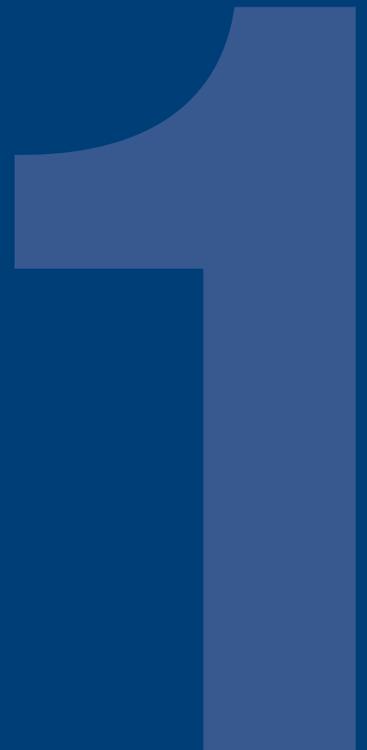
Part two

| | | | |
|----|---|----|---|
| 54 | About the the Taskforce on multiple conditions | 67 | Desk Research and Knowledge Download Workshop |
| 55 | What does this research tell us about how people experience living with long-term conditions? | 68 | Sample breakdown |
| 60 | Important areas not addressed by this research | 69 | Interview approach |
| 61 | How we can respond to the challenges identified? | 69 | Areas of questioning |
| 66 | Appendix 1: Participant conditions | 70 | References |
| 67 | Appendix 2: Full methodology | | |

Part one

Ethnographic Research Report

Prepared by Revealing Reality for the Taskforce on Multiple Conditions



Executive summary

This report sets out the findings of an ethnographic research project to understand how it feels to live with multiple long-term health conditions (MLTCs). The research was conducted by Revealing Reality for the Taskforce on Multiple Conditions, who work to better understand and address the growing challenges facing those living with MLTCs and their interactions with the health and social care professionals that support them.

In-depth interviews were conducted at home with 10 people living with MLTCs, covering a range of demographics and locations across England. Interviews were open ended and informal and sought to understand participants' everyday experiences of MLTCs and their perceptions of their quality of life. The research covered participants' interactions with the health and care systems, understanding both positive and negative experiences they had had. It also explored support networks, coping strategies and the changes participants had made – or had been forced to make – over time.

The individual stories uncovered are powerful and varied. All the participants have had their own ups and downs, better days and worse. They often described their experience of living with multiple health conditions in terms of what they have 'lost' over time, most frequently a loss of mobility and the social connectedness that comes with the ability to get out and about and engage in social activities. They also tended to experience an increase in physical pain, and a decrease in mental wellbeing. In many cases people felt stuck, with limited options.

Despite this, the participants did sometimes find their own ways to take control and manage their situations. By adapting and developing coping strategies, they could regain some agency and make decisions about their conditions and their lives. For some, this involved developing self-management strategies and actively selecting care that felt relevant to them. In other cases, participants focused on reducing their 'health bandwidth' and creating ways that their work, hobbies and daily routine could suit their changing health situation. Maintaining and expanding meaningful relationships with family and friends – particularly those who supported their independence – also helped many of the participants to cope, as did developing strong and productive relationships with health and social care professionals.

The development of coping strategies was, however, time consuming and required effort and energy that not everyone was able to give. Wider circumstances made it more difficult for some to adapt, often leading to further challenges and complications. While these circumstances of course differed from person to person, and could have been affected by age, gender, socioeconomic background and living situation, there were certain experiences that were seen to consistently make managing multiple long-term conditions more difficult. These included: Reduction in mobility, chronic pain¹, shrinking social networks, losing the ability to engage with work as it is typically structured, and lower mental wellbeing.

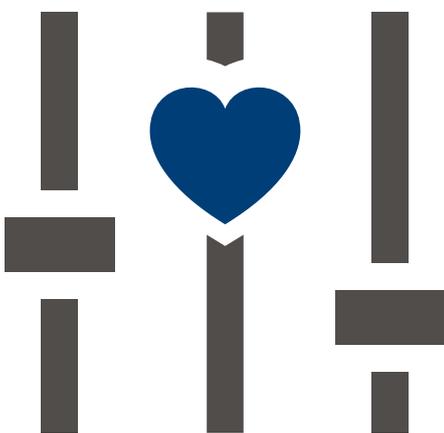
While these experiences are not predictable as such, they were widespread and could have serious consequences. Efforts to reduce – or ideally prevent – these experiences are likely to have a beneficial effect. Supporting people to take control of their health, recognising mental wellbeing, helping prevent loss of mobility, encouraging critical reflection on support and clarifying how the system works could all help lead to improved outcomes.

There are significant transitional moments where such support can have a life-changing effect on the trajectory of a person's experience. To ensure these moments are not missed, it may therefore be helpful to consider all interactions with someone with several long-term conditions as an opportunity to apply a set of principles that could be considered by care professionals, charities, support groups, carers and the individuals themselves:

- 1.** Promote mobility: By its nature, mobility is often ignored until it is a problem – by which time it is more difficult to address. Actively promoting the maintenance of mobility – including among healthy people – could bring great benefits.
- 2.** Encourage the person to take an active role in the management of their conditions: Life with multiple health conditions can be frustrating, confusing, and can lead people to feel they are a burden on the system and their loved ones. This can be offset when people feel empowered in their own health care, and their wider life, whether this means them being better supported to navigate the system, feeling able to ask questions and knowing who to ask, or having shared conversations with health and care professionals.
- 3.** Help the person identify achievable goals: Making goals, feeling purposeful and having routines can all affect somebody's mental wellbeing. Living with multiple health conditions can make these things harder. Taking an approach that goes beyond the clinical setting, could help people realise that when old goals are lost, new goals can still be made.

Underpinning these principles is the fundamental need to consider lives and experiences as holistically as possible – taking account of physical health, mental wellbeing and quality of life. It is important to stress that these principles are not reserved only for interactions with people who have several long-term conditions. While the intersection between multiple conditions affects people's experiences, the ways and means of maximising the likelihood that they will be best placed to adapt can – and should – be established as soon as a person is diagnosed with a single condition.

REVEALING REALITY



Supporting people to take control of their health, recognising mental wellbeing, helping prevent loss of mobility, encouraging critical reflection on support and clarifying how the system works could all help lead to improved outcomes.

Introduction

What is it really like to live with several long-term conditions that can be managed but not cured?

How does it affect someone if they are in near constant pain or their mobility has been severely curtailed?

In what ways do the cumulative effects of multiple conditions affect people's relationships, mental wellbeing and daily life? How and why do these experiences differ?

How could the health and social care systems support these people to continue to lead the lives of their choosing?

Around 15 million people in England have a long-term condition, and the number of people living with several of these conditions is growing. Estimates range from 15 to 30 per cent of the population,² with the proportion highest among older people, who also tend to have more conditions.³

People living with several conditions not only have to manage each one, but also the consequences of the ways in which they interact. Having multiple conditions can mean that symptoms are magnified, the effects of drugs and their side effects are more complex, and the cumulative impact on people's physical and mental wellbeing can be heavily felt.

Many people are in chronic pain or suffer from reduced mobility, both of which can cut across all their day-to-day experiences. Their social networks may have shrunk, and they may be unhappy, isolated or feel they lack purpose. It can feel as though the conditions – their effects and the effort of managing them – have taken over much of their lives.

However, some people with multiple long-term conditions may find they are able to develop ways to lessen their impact, assert control over their management or adapt positively to their changed circumstances.

Unfortunately, our health and care institutions are, in most cases, not structured to deal with this growing challenge, and opportunities to provide the most effective support so that more people feel better able to cope, are too often missed.

Care and services are often siloed or fragmented; still largely delivered based on the condition rather than the person and focusing on physical symptoms rather than physical and mental wellbeing.

People are, in many cases, given medication and instruction, but are rarely asked what treatment or care they would most value, nor encouraged to set themselves achievable goals that could help them feel better.

Recognising this growing challenge – and the scope to inform or influence the design and delivery of services – the Taskforce on Multiple Conditions⁴ was established and commissioned this research to help inform its work.

Exploring in depth the lived experiences of people with multiple long-term conditions – which has previously been lacking in research that has instead focused on clinical perspective and interventions⁵ – is necessary to identify missed opportunities for charities, policymakers and health and social care professionals to better support them.

This research therefore aimed to uncover the living situation for people with multiple conditions; exploring their interactions with the healthcare and social care systems, understanding their perceptions of their quality of life, revealing their support networks and their ways of managing their conditions.

There has previously been insufficient information on people's experiences to identify exactly what action is required.⁶ This research set out to identify what matters to people with multiple conditions in relation to the provision of care and support.⁷

Considering individuals' experiences over time has helped illustrate that it is not the specific conditions, nor even the number of conditions a person has, that makes the greatest difference to people being able to manage their changing health conditions, but instead how they are supported and cared for.

This report starts with those individuals; describing their unique experiences of living with several conditions over a long time. It illustrates the highs and lows, the 'losses' they faced because of their conditions and the ways in which they adapted to cope with or improve their situation.

This detail helps to identify what helps or hinders people to make changes and adapt to life with multiple conditions, and to consider opportunities to provide more effective support.

Considering these issues thematically provides the link between the individual and the system, paving the way for recommendations that are relevant to health and social care professionals, policymakers, advocates, carers and, of course, the people living with multiple health conditions themselves.



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Method

The purpose of the research was to hear the voices of people living with multiple long-term conditions and to understand their lived experiences. The research used an ethnographic approach with a small number of participants.

A long-term condition is a condition, physical or mental, that cannot be cured but the symptoms and complications can usually be controlled with treatment.

To ensure the research built on existing knowledge relating to patient experience of multiple conditions, existing literature sources were reviewed, helping to inform the sample design, interview content and the framing of the project to participants.

Sample

The target sample for this research was necessarily broad: People living with two or more long term health conditions. The 10 respondents were recruited from various locations across the UK, ensuring a spread of rural and urban settings. They were selected to represent variation in terms of their conditions, age, gender, ethnicity, socio-economic grade, living situation and type of support network. Given that certain demographic features are already known to strongly correlate with living with multiple health conditions, effort was made to include the voices of a range of different people and hear about the ways in which experiences were similar or different.

Care was taken to ensure that a range of long-term conditions was represented within the sample, as well as variation in the number of conditions each respondent suffered from. Appendix 1 contains a full list of the conditions respondents had been diagnosed with.

To find participants for this project, an external recruitment agency put forward over 30 potential participants for the research. In-house street recruitment was also conducted in Southwark and Lambeth. The final participants included individuals who were: working age with no dependents; working age with family; retired with a partner; retired and living alone; elderly with a partner; and elderly and living alone.

Interview approach

Each participant was interviewed in depth in their own home. Discussions lasted for between three and four hours. This allowed time to build rapport and to make participants feel at ease with the interview process, as well as enabling the development of in-depth profiles that include living situation, home environment and wider lifestyle.

During the interviews data capture tools were used to understand participants' everyday experiences and perceptions of their quality of life. The fieldwork explored people's support networks, coping strategies and their interactions with the health and social care system, both positive and negative.

The term 'multi-morbidity' – and the use of other detailed medical terminology – was avoided during interviews, with the aim of uncovering the words and phrases that participants used themselves to describe their situations and experiences. It was essential that the language used was familiar to ensure participants felt that questions and issues were relevant to them. As the interviews progressed, it became clear that the term 'multi-morbidity' was not only unfamiliar but also elicited strong negative reactions from most participants, who associated the term with death and finality.

Analysis

Analysis was conducted from the start and throughout the project, with feedback and discussion of what was heard from the respondents, coupled with photographic evidence and 360 footage to bring the stories to life. From these discussions, key themes surrounding the lived experience of multi-morbidity were identified and explored and the report was structured.

This ethnographic research was designed to capture and convey the experiences – day to day and over time – of people living with multiple long-term conditions. In order to make sure this research captured a range of experiences, we deliberately chose a sample that included individuals in a variety of different situations. Whilst the social context in which each respondent lives forms part of their stories, the size of the sample means we can't draw conclusions based on these social factors. However, the narratives in this report could inform the development of further quantitative research.



“

I still work because it means I can stay fit, feel useful and gives us the bit of money we need to run the car and remain independent. I've got my family: You can't ask for much more than that.

Peter, 81

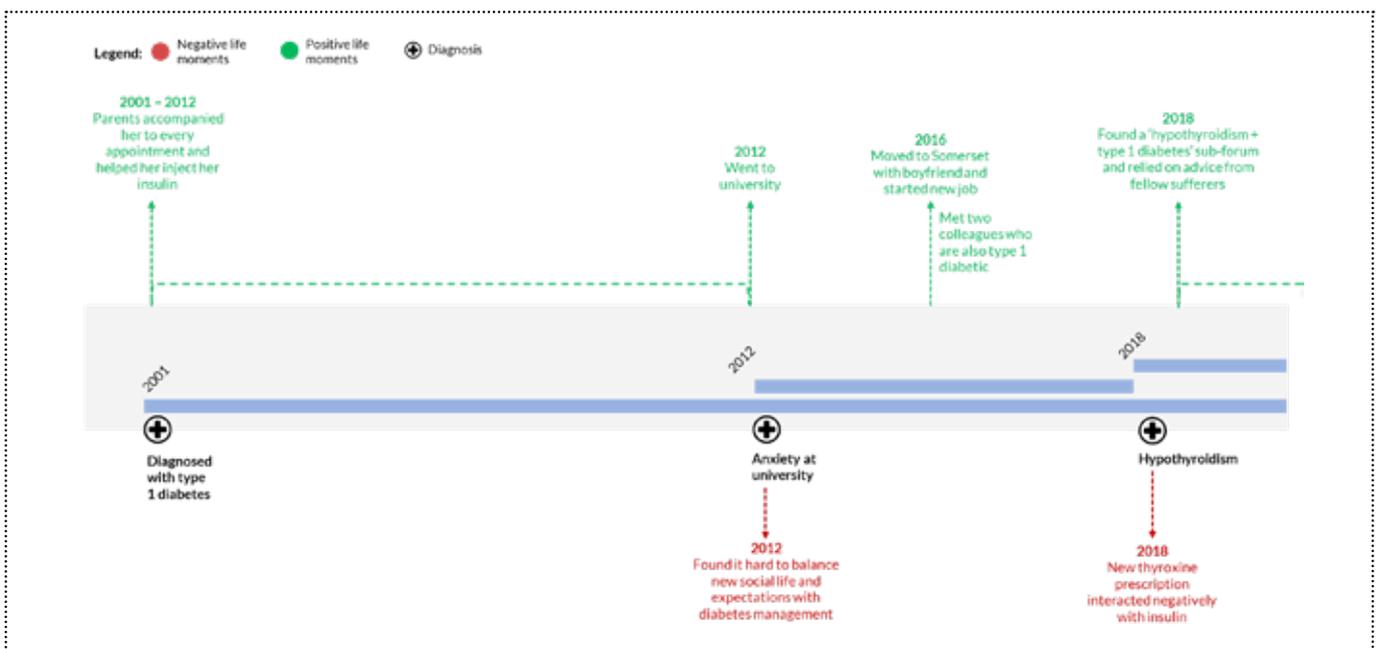
Living with multiple health conditions

Several hours were spent with each of the 10 study participants in their own homes, discussing their experiences and feelings and observing them as they went about their daily activities.



“ So, I’ll have to take a tablet every day for the rest of my life to control my thyroid. Frankly, that’s nothing compared to diabetes.

Anna, 24, Somerset⁸
Type one diabetes, hypothyroidism



Anna was diagnosed with type one diabetes aged seven. Growing up in Birmingham with her parents and younger sister, her mum and dad helped her control her condition and accompanied her to all her medical appointments.

She had been under the care of the same paediatric diabetes specialist until she was 18, when she went away to university. This life change was difficult for Anna; she found it harder to balance managing her condition with a student lifestyle away from her parents and trusted doctor. As a result, Anna suffered with anxiety during this time. Anna still sometimes struggles with being so young and having to monitor her health constantly and feels different to her friends.

After university, following a brief stint living in Cardiff, Anna and her boyfriend have settled in Somerset. She works in HR for the civil service, splitting her working days between Cardiff, London and home. Her boyfriend works in football coaching. They feel financially stable and have just purchased their first property together.

Anna's mum, with whom she speaks every day on the phone, still lives in Birmingham with her step-dad, who used to be a GP. Her dad now lives in Portsmouth. She sees everyone in her family regularly.

Anna injects insulin between four and 10 times a day. She has a Libre sensor, worn on the upper arm, which, when scanned, gives a glucose reading. The sensor is designed to eliminate the need for routine finger pricks. Anna was part of a trial for this product and, after the trial was over, she decided to pay for it. It costs her £200 a month. Anna is desperate to get an insulin pump – a portable device attached to the body that delivers constant amounts of rapid or short acting insulin via a catheter placed under the skin – to give her more control over her blood glucose levels. Anna describes her overall control of her diabetes as excellent, however, she believes that she sometimes does not receive the best diabetes care. She feels that precedence is given to those who do not manage their diabetes as well as she does, or who have been diagnosed more recently.

“It’s frustrating that no matter how self-controlled I am, my resistance to insulin will grow and there’s nothing I can do to stop that.”

Two months ago, after a series of tests, Anna was diagnosed with hypothyroidism, a result of Hashimoto’s disease. Anna had been familiar with the condition already, as her mother also has hypothyroidism and it is frequently associated with type one diabetes. Anna did not feel as though this secondary diagnosis would make much of a difference to her life because she already knows what it is like to have to monitor her health daily. To her, hypothyroidism is just a small addition to her ‘primary’ condition.

“So, I’ll have to take a tablet every day for the rest of my life to control my thyroid. Frankly, that’s nothing compared to diabetes.”

Anna had a bad experience when she was prescribed thyroxine to treat her hypothyroidism; it interacted negatively with her insulin, making her blood sugar rise. A new GP Anna had registered with, and who was carrying out the tests for hypothyroidism, another autoimmune condition, had not told her about this possibility, despite knowing that she was diabetic. Over a month-long period, Anna tried to get in touch with the diabetes team at her new hospital, but no one called her back. This prompted her to register with a different hospital.

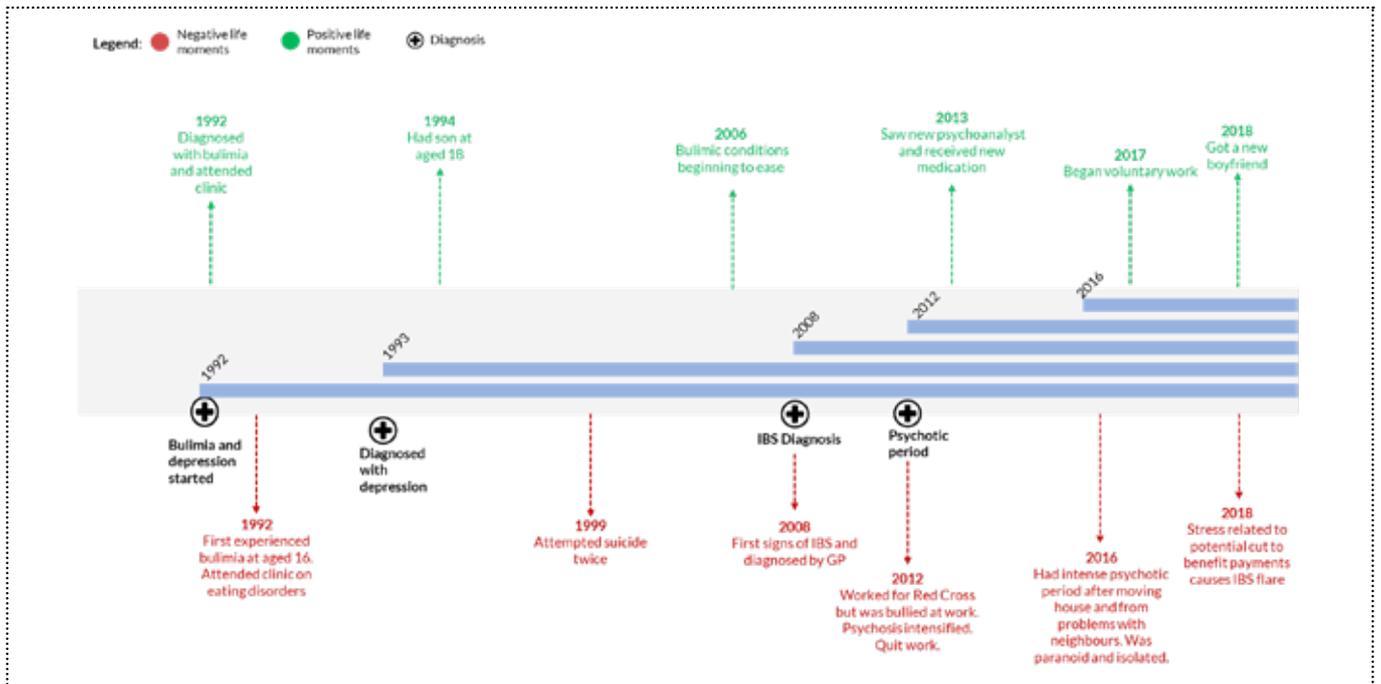
Anna is worried that she is more likely to get more conditions (she also suffers bouts of psoriasis). She knows somebody at work who is type one diabetic and was recently diagnosed with MS, and she fears this could happen to her in the future. She also worries about the possibility of having a risky pregnancy. Anna is keen to start a family within the next few years.



“ I’ve got more routine now than I have had for years.

Megan, 42, Lambeth

Depression, bulimia, psychosis, insomnia, IBS



Megan lives alone in Lambeth. She is unemployed but regularly volunteers in mental health cafés and art groups. She is hoping to be an art therapist within a year. She has a boyfriend, whom she met within the last 12 months, and a 24-year-old son who studies IT consultancy at university in Colchester.

“I don’t really have many people to talk to about my mental health. I don’t have many close friends, my natural state is to be alone, but I do want to be around people. I talk to my son about it when I see him, every few months, we’re really close. I don’t talk to my boyfriend as I haven’t been with him very long and I don’t think he’d really understand.”

Megan's upbringing was split between England and West Africa. She was born in England before travelling around West Africa until she was 16, when her family moved back to the UK. Her mental health conditions started when she moved back to England and watched a programme that contained a segment on bulimia, her first exposure to the condition. In the months to follow, she started suffering from bulimia herself. Subsequently, she also became depressed. At 18, she had a child. Her first medical treatment was in 1998, when she attended a bulimia therapy course for eight weeks to which she had been referred by her doctor.

Since then, she has had various episodes of intense psychosis, for which she has received various treatments and medication. Most recently, two years ago she had a crisis and was suicidal following a move to Lambeth, due to the stress of moving and problems with her neighbours. During this time, she was referred to a crisis team and then to a mental health team. Currently she sees a Lacanian psychoanalyst weekly, while taking three forms of medication (for psychosis, depression, and insomnia). As part of her recovery, they recommended she attend mental health cafés to meet new people.

“I've got more routine now than I have had for years. My volunteering at the cafés and art Mondays, and then my therapist on Wednesdays means I have a bit more structure.”

Combined, these strategies have all meant she is now relatively stable, though stress does sometimes trigger her insomnia and paranoia.

“My son and my art saved my life, they gave me reasons to live when I was really psychotic.”

Megan also suffers with IBS, which is influenced by her paranoia and insomnia. Indeed, when she faces external stresses, these conditions seem to flare up and to aggravate each other. For instance, recent worries about the possibility of her disability benefit payments being reduced (as she wants to be employed part-time by one of the cafés that she volunteers for) has caused her IBS to worsen, as well as triggering bouts of insomnia and paranoia.

“The thing that has been stressing me lately is my benefits. I have a review of my benefits soon because I want to get paid for my work at the café. You are allowed to get paid for a bit of work without losing your benefit, but they need to review it.”



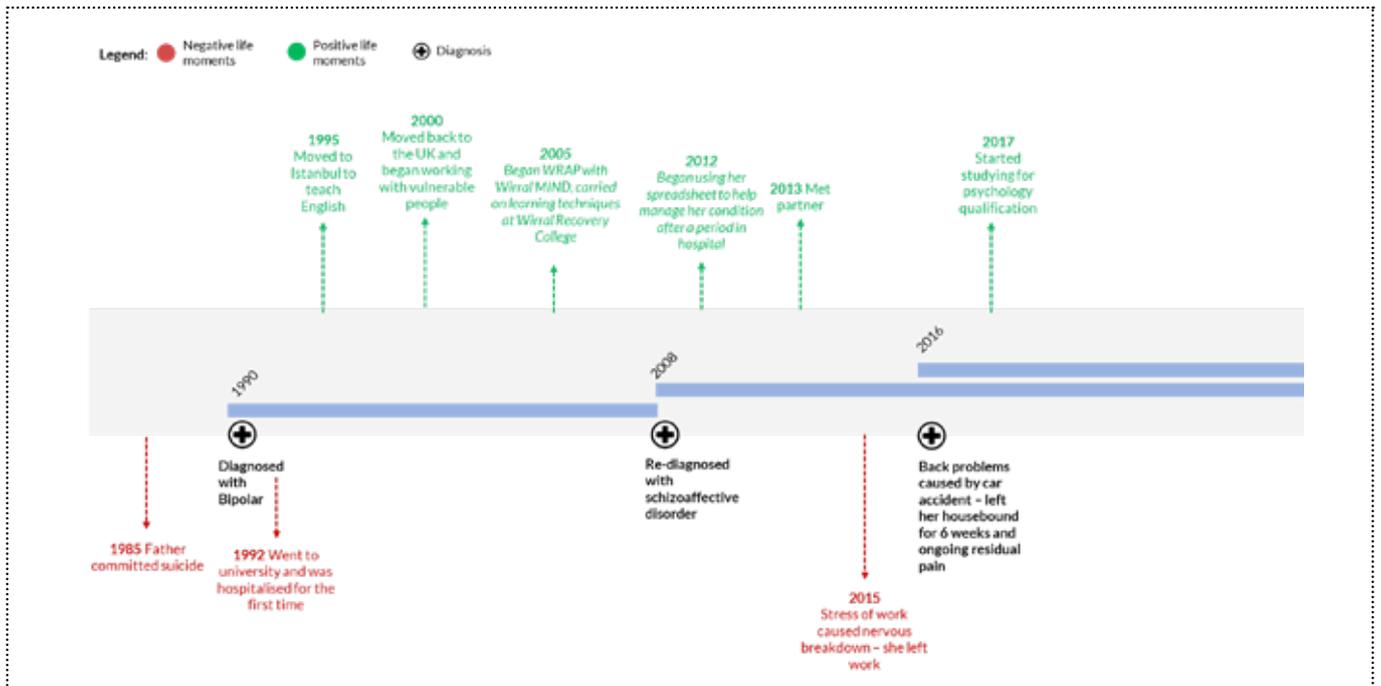
“ My son and my art saved my life, they gave me reasons to live when I was really psychotic.”



“ I’m happy having a label as long as I’m not just a label.

Wendy, 44, Wirral

Schizoffective disorder, sciatica, asthma



Wendy lives alone with her two cats in the Wirral. She has a partner of five years living nearby, whom she met on a dating site, as well as a 17-year-old stepson. Wendy was first diagnosed with bipolar disorder when she was 16. Her father committed suicide when she was 11, and she believes that this played a role in her mental condition, although she remembers having mental difficulties before this event.

Wendy went to university at age 18 and became very ill during her first year, leading her to being hospitalised on a psychiatric ward for the first time. She has had two long-term psychiatric hospital stays since then. About 10 years ago, after finally being open about her psychotic symptoms, Wendy was re-diagnosed with schizoffective disorder. She has come to terms with her mental health condition and speaks very openly and proudly about it, however, sometimes she fears the stigma attached to schizoffective disorder, particularly its association with violence by the media. She wants to be seen as more than her health.

Wendy experiences extreme highs and lows as well as psychosis. Though generally stable, she generally suffers around three or four very serious periods of mental distress every year and, though well supported by friends and family with advice, listening and accompaniment to appointments, often feels burdensome.

“On bad days I’ll consider taking my own life. I’ll consider getting on a train to a faraway town and never contacting people again because then they won’t have to deal with the pressure of having me in their life. It is a constant battle to accept that other people worry about me and that I need to ask for help.”

Wendy relies on the support of her best friend and of her partner and has a number of coping strategies in place to help her manage her conditions. She has lists of things that make her happy dotted around the house to keep her spirits high and an excel spreadsheet which she updates daily with behaviours that she recognises as unhealthy. If these triggers go over a certain number, the cell will turn red so that she knows to call her friend or partner to come and check up on her. She also feels well-supported by her local community; she enjoys the fact that people take the time to get to know each other where she lives. She feels more comfortable that people around know that she has a mental health condition and might need a bit of assistance from time to time and likes having familiar places built in to her routine.

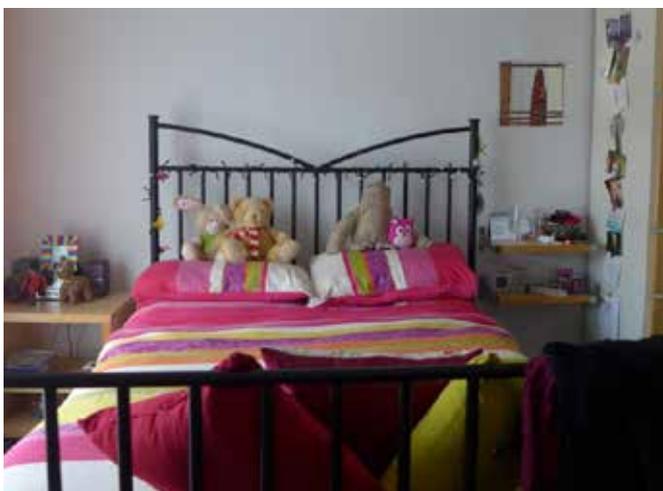
After finishing university, Wendy moved to Istanbul for five years to teach English as a foreign language. When she returned, she got into working with vulnerable people which she found an *“honour and a privilege”*. However, after 15 years in the homeless sector, Wendy’s case-load had increased to an unbearable level. She eventually had a nervous breakdown, causing her to leave work. During this time, Wendy was involved in a car accident and then suffered a nasty fall, in which she broke several bones. She was immobile for a short period and in constant pain, and this had an impact on the way she felt about herself and her relationships.

“I have fought all my life to be independent. But when the pain started, I couldn’t. It felt in that dark period like I’d never be independent again.”

Although improving, Wendy still has residual physical pain and still attends a pain clinic. She finds it difficult to cook for herself as she must bend down to reach her cooker. She also still has to go up her stairs on her hands and feet. The physical pain caused her extreme depression and stopped her from coping with her mental health as well as she had learned to.

“I’m comfortable with schizoaffective being a part of me. But the physical pain, it affected my personality. It made me an angry person and someone I didn’t recognise.”

Wendy has really fought to pull through. She is currently studying for a psychology qualification and hopes to start an MA in September 2018 in addiction studies. She does not think she will be able to return to ‘frontline’ work but is hoping to possibly get a job in research. She wants to be able to achieve a good balance between work and pleasure, as well as make some financial improvements.



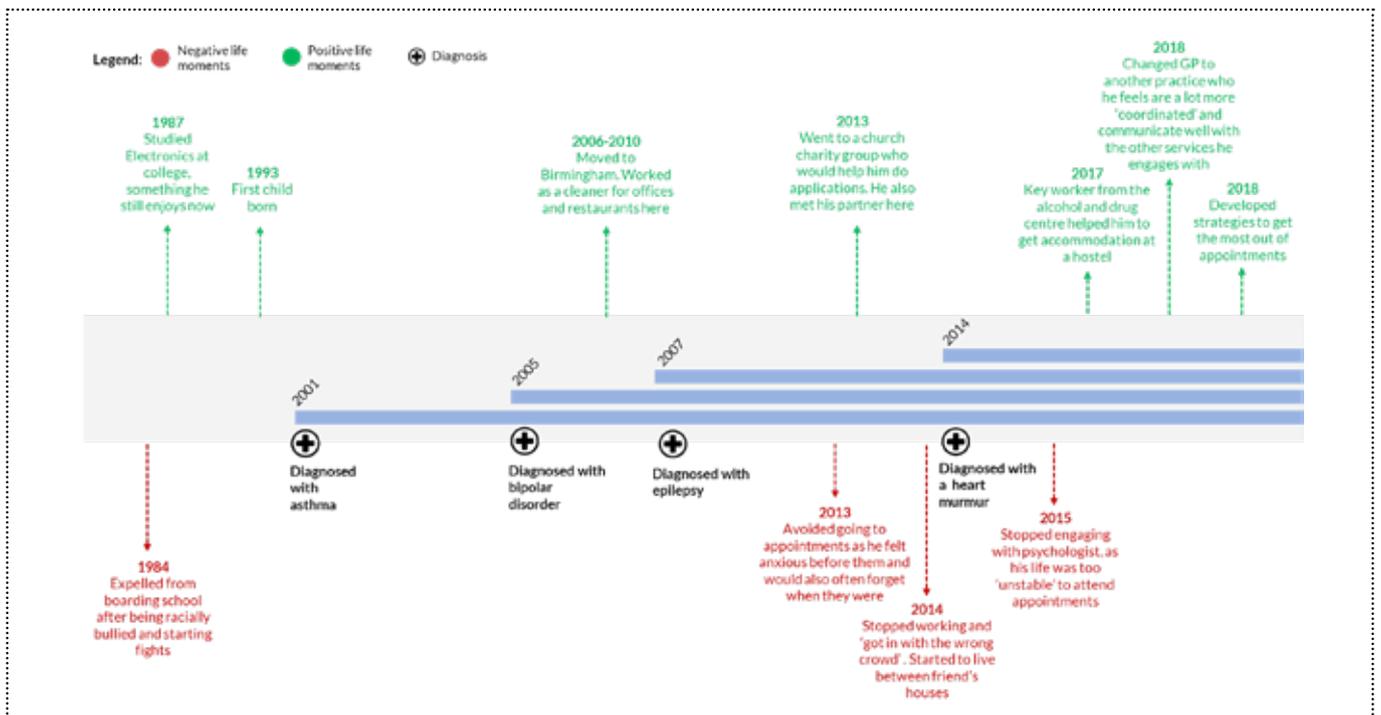
“ It is a constant battle to accept that other people worry about me and that I need to ask for help.



“ You get more done when one organisation deals with the other directly, it is easier.

Paul, 47, Lambeth

Asthma, bipolar disorder, epilepsy, anxiety, heart murmur



Paul lives in a hostel in Lambeth. He moved to the hostel after spending a year at various friends' houses and some time on the street. He has a 25-year-old daughter from one partner and a 21-year-old son and a 19-year-old daughter from another partner. One of the reasons he likes living in London is that he can easily visit his family members, however, he would like to move to the outskirts where he could be “away from the hustle and bustle”.

Paul is currently out of work, but was employed in the past as a labourer, cleaner and delivery driver. While he enjoyed the delivery driving and the different people and places he visited, he ended up getting in with “the wrong crowd” and developed a drug addiction just over 15 years ago. He misses having a job more than anything else and is hoping to get back into work once his life is more stable.

“I felt worthy, I felt like I was doing something and that is what I miss.”

Paul was diagnosed with asthma in 2001. A few years after this he was diagnosed with bipolar disorder, although he still struggles to understand this diagnosis, as labels such as *“chronic depression”* are frequently used to refer to his mental health instead. For a long while before his diagnosis, during the 80s and 90s, he felt uncomfortable talking to anyone, family or professionals, about his mental health until it became too much for manage and he realised he was self-medicating with drugs and alcohol.

“Like a pressure cooker you can only hold so much to yourself and then you explode.”

In 2007 he was diagnosed with epilepsy which, although now largely under control, is a great source of fear and embarrassment for him when he experiences seizures. Most recently, in 2014, he was diagnosed with a heart murmur.

Due to the instability in his life, which stems primarily from recovering from a drug and alcohol addiction and living in temporary accommodation, Paul finds it very hard to think about managing his multiple health conditions. He does attend ECG scans to monitor his heart every three weeks, but he finds it more difficult to communicate with mental health practitioners. In particular, he finds it hard to engage with psychologists that he is referred to for his bipolar disorder, as he feels they put pressure on him to work to change his living situation instead of helping him understand how he is feeling. As someone who often feels overwhelmed by the number of steps he needs to take to get his life on track, Paul can sometimes come away from such appointments feeling as though he is failing.

“You could have 10 things you know you need to do but you can’t do them all so you set yourself up to fail.”

He has, however, developed a set of *“tricks”* that he uses to get the best out of the health care system. He is lucky enough to have family live close by and often asks his sister to come along to appointments with him. He finds that her being aware of the appointment makes him more likely to go to it and not talk himself out of it. In addition, she helps him to remember what he wanted to talk about in the appointment and not shy away from more difficult issues. However, he often worries that he is a burden to his family members.

“My family all can help for a little while, but I felt like I was imposing.”

He has found that getting organisations to speak to each other and among themselves rather than him going straight to an individual healthcare professional has got him better, faster results. His key support worker from the recovery centre he attends has been influential in helping these interactions happen. For example, Paul will often get his support worker to liaise with the staff at the hostel he is living in, his GP and with people at the council.

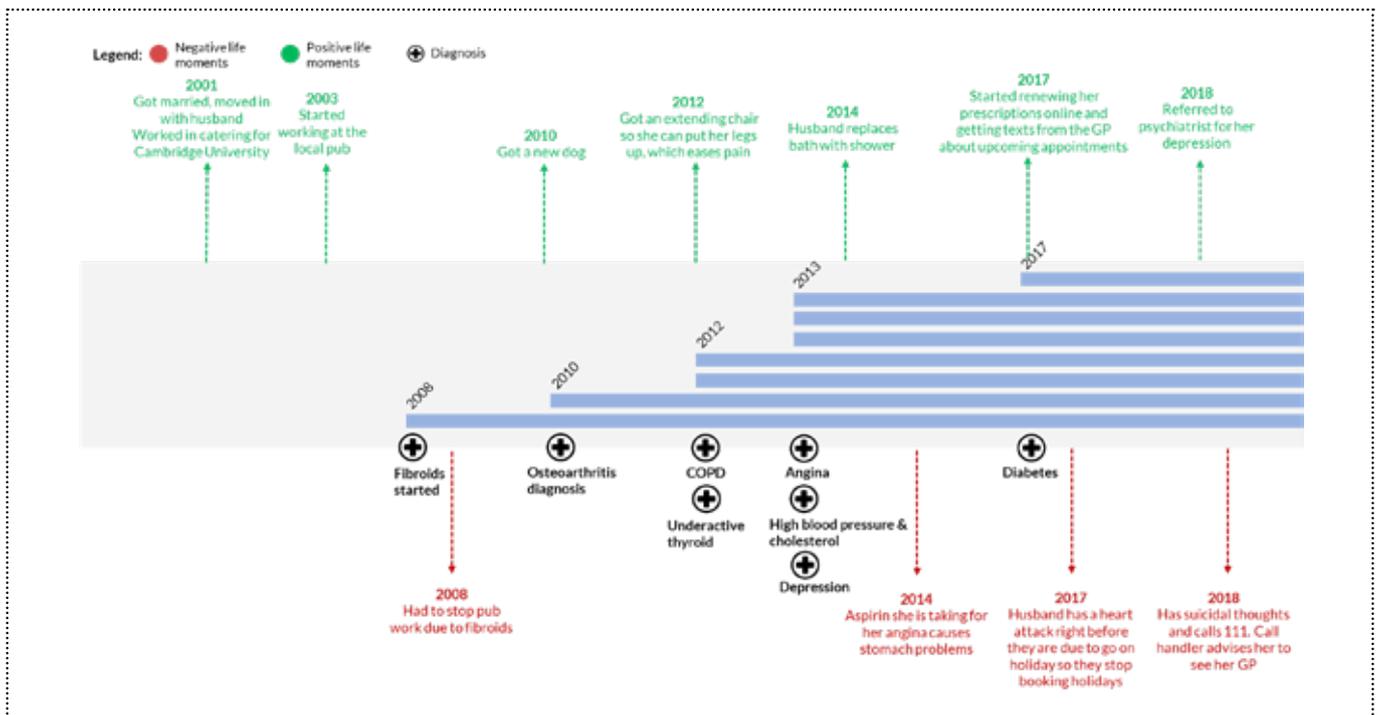
“ Like a pressure cooker you can only hold so much to yourself and then you explode.



“ Deep down it is as if I can’t be myself. I am half my health and half me.

Susan, 53, Cambridgeshire

COPD, type two diabetes, hypothyroidism, depression, high blood pressure, high cholesterol, osteoarthritis



Susan lives with her husband and their three beloved dogs in a village in Cambridgeshire. The couple love animals and their honeymoon even started in a zoo. They own their house and have lived in it since they got married 17 years ago after meeting online. Susan also grew up in Cambridgeshire but has been estranged from her mum and brother for many years.

Susan used to work as a catering manager at a university, where she had a close group of friends she would often socialise with. She had to stop working in 2008 when she got fibroids and was bed ridden for two weeks at a time. Since stopping work Susan has been diagnosed with osteoarthritis, COPD, hypothyroidism, angina, high blood pressure and high cholesterol, depression and diabetes, in that order. She takes 14 different medications every day and her illnesses can feel as though they consume her life.

Susan is in constant pain from osteoarthritis. On some days she finds it hard to stand for more than five minutes, so she spends most of her days sitting in a chair with the foot rest extended which tends to help her knees and she carefully places cushions for her arms to reduce the pain. Susan describes the pain as “*fogging up*” her mind and making it hard to focus on anything, as well as hard to care about, or notice, her other conditions, when the pain is so predominant.

“It is like someone is constantly hitting me with a cricket bat in my back.”

She spends most of her time in her living room playing games on her phone, making crafts or watching crime series on TV. Susan cannot predict how well she will feel on a day to day basis, so tends to avoid making plans as she often will have to cancel them. This means she sometimes feels like her life has become very repetitive.

“I just have to take each day as it comes. Planning doesn’t work.”

Susan is reliant on her husband to care for her. He, however, is also struggling with multiple long-term health conditions, including Type two diabetes, hypertension, enlarged prostate, diverticulosis, brittle bones, depression and ventricular fibrillation. He is more mobile than Susan and still works as a maintenance engineer. They try to manage their conditions together as best they can by getting joint appointments and picking up their medications together. Susan’s husband has done several DIY home adaptations, as he can “*see what she needs*” so will “*find a problem and think of a solution*”. For example, to avoid Susan having to bend over around the house, he has attached wheels to all the furniture so that she can push them away when she is hoovering and attached an extender plug socket to the wall. Another reason Susan’s husband chooses to make these adaptations himself, rather than ask for any help, is that he worries it would be expensive to get home adaptations fitted.

Susan gets healthcare support from one GP that she has known for a long time. She likes to see this doctor because he knows about her case and the complications of having multiple illnesses. If she does see other consultants, she does not like to bring up her other conditions as she believes it is not relevant.

“I’d rather just see my GP, I know him and he knows me, if I see someone else I’d just have to go through it all again.”



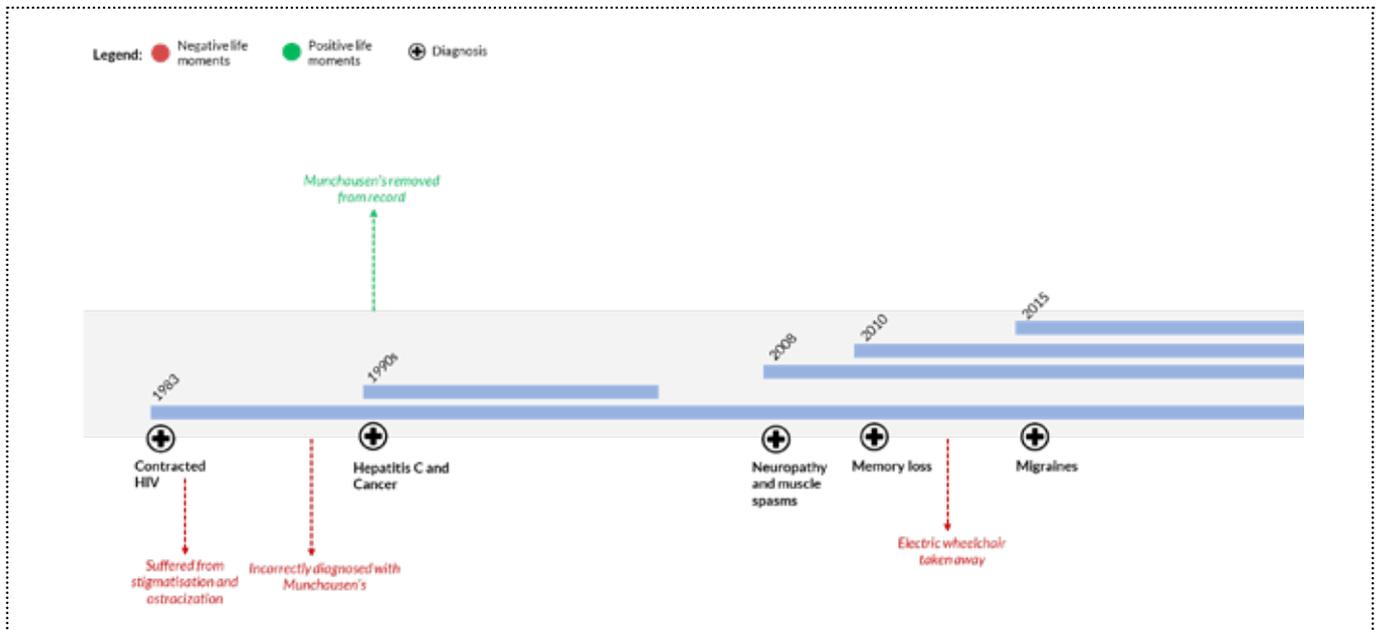
“ You look at the medical report and think what the heck does that mean, so it is easier to wait and see the GP who can explain it in layman’s terms.



“ I miss going out for a walk. Long walks are rare. It can take me 3 or 4 days to recover.

Matilda, 55, Peak District

HIV, depression, avascular necrosis, peripheral neuropathy, HIV related memory loss



Matilda lives in the Peak District, where she originally grew up. She lives with her landlady, a good friend on whom she relies for help, however, she regrets that she has lost other friends over the years due to immobility and illness:

“In the past I could have named the people I considered friends in the hundreds. It’s remarkable how fast they disappear when you’re not able to travel to meet them. The fact is they’ve not been there.”

She moved to Coventry at age 18 to go to university. Here she began working in the music industry and got involved with taking drugs. She contracted HIV in the early 1980s. What followed was a period of intense illness, social stigma, and mistreatment by doctors, including an incorrect diagnosis of Munchausen’s disease. She worked with lawyers from the Terrence Higgins Trust to have this diagnosis eventually expunged from her record. She still experiences what she calls “white coat syndrome”, whereby she feels anxious when she sees the doctor, and therefore avoids it if she can.

“I have ‘difficult patient’ across my records. I hate going to the hospital, so I avoid it at any costs. I have had some fairly dreadful experiences with hospitals.”

During her twenties and thirties Matilda worked in various jobs including residential social work and outdoors expeditions and bush-craft, but she had to give up work as she became increasingly ill with neuropathy and muscle spasms, causing her pain and immobility every day.

“There is not a bit of my body that doesn’t hurt. I have constant pain from my foot to above my knee and my hand to above my elbow. That’s neuropathic pain. And then I also have degenerative necrotic bone disease in the long bones.”

Matilda also suffered HIV-related memory loss. Matilda is also prone to infection as her T cell count is very low, and she suffers serious migraines about once a month, ending up in hospital several times as a result. She still occasionally sees doctors; once every month or every few months, she makes the 25-mile journey to Sheffield to attend the HIV clinic. Here she gets her T cell mark checked and gets her HIV medication. She has only recently gone back on to HIV medication, after her T cell count became extremely low two years ago.

“It’s not that the doctors make you take it. But they basically said, ‘you either go on it or you die’, at which point you say yes.”

In the 1990s Matilda was on azidothymidine, however, she believes that some of the bone and joint problems she experiences may be related to the drug. Whilst she doesn’t always adhere to her HIV medication, she relies heavily on her morphine prescription from her GP, which is reviewed every six to 12 months. She has also been attending a pain clinic on and off for four years and receiving Talking Therapies treatment, but she believes living in a rural area has prohibited her from receiving the best care.

Matilda tries to keep herself busy with hobbies such as whittling, hand-bell ringing and acting as the admin on several Facebook groups. She has a therapy dog, who she tries to walk as far as she can. When Matilda originally got HIV, she was told she would not live long. She believes that this is why she never makes long-term plans or goals.

“I miss going out for a walk. Long walks are rare. It can take me 3 or 4 days to recover. And I can’t predict when I’ll feel able to do a walk, so I can’t plan to meet up with anyone. It happens once a month, enough that it staves off desperation”

Matilda still speaks to her parents regularly, who live close by. She has never been open with them about her HIV diagnosis, however, and struggles knowing that this has been a secret.



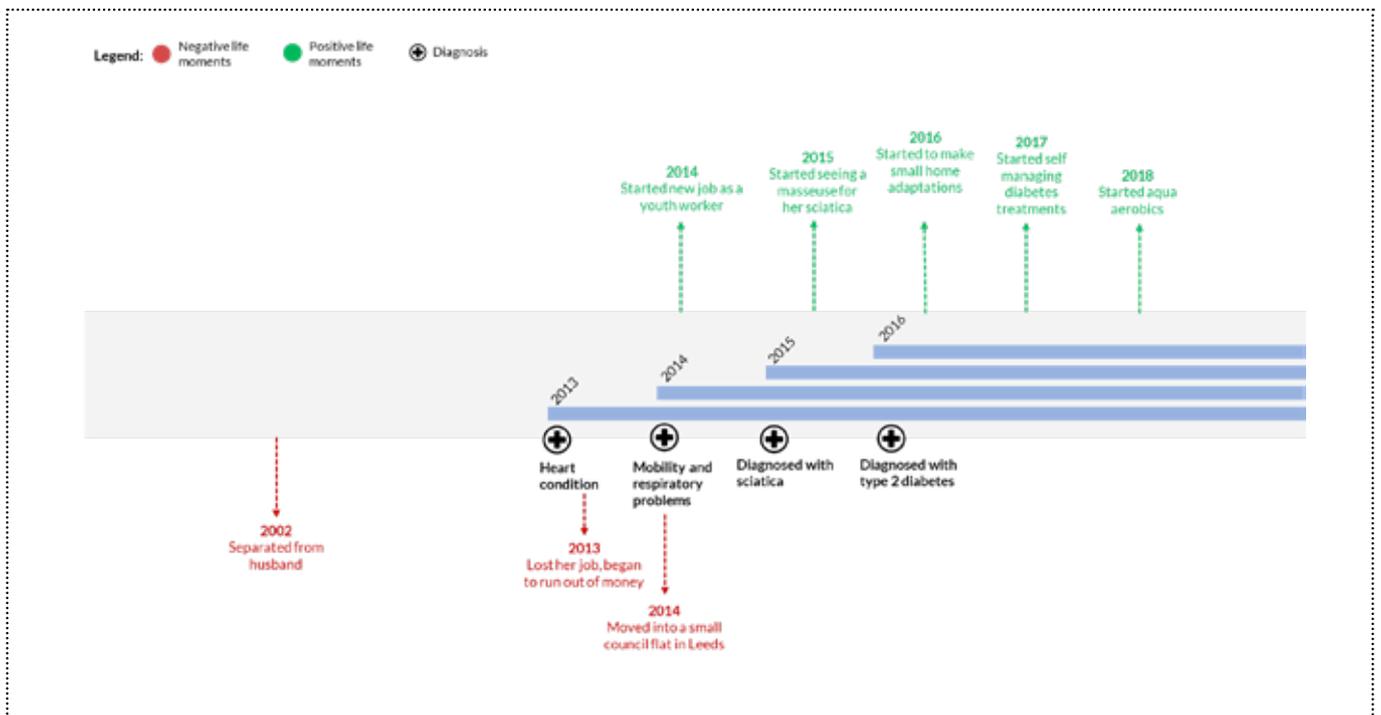
“ It’s not that the doctors make you take it. But they basically said, ‘you either go on it or you die’, at which point you say yes.



“ If I can sort something without taking medication for it, I will.

Vivienne, 55, Leeds

Type two diabetes, respiratory problems, sciatica, high blood pressure, unspecified heart condition



Vivienne is a youth worker who lives in a small apartment on the outskirts of Leeds. She moved in to the flat five years ago, after spending six months in hospital following major heart problems. During the six months she was hospitalised, Vivienne’s life changed dramatically; she went from being a high flying international training consultant, to having no job, very little money and being moved into council housing. She has however worked hard to rebuild her life and would like, one day, for it to return to what it was before she got ill.

“I could have gone to Spain for lunch if I fancied it, then things changed very quickly.”

Vivienne can’t remember the name of her heart condition, and she isn’t particularly interested in finding it out. She has, however, had long lasting mobility and respiratory problems. She gets tired and cold very easily, often feels stiff and finds it particularly difficult to manipulate her fingers and toes. Her daily pain and mobility issues were compounded in 2015 when she was diagnosed with sciatica. Shortly following this diagnosis, she also became type two diabetic.

Despite having multiple long-term health conditions, Vivienne's interactions with health and social care professionals have been minimal. Her most regular and significant interaction with a doctor is her three-monthly check-up and blood test for her diabetes. Despite attending these check-ups, engaging with her doctor and collecting her prescription, Vivienne has not been taking this medication. Instead, she has been stashing it and throwing it away once it has accumulated. Vivienne has a lack of trust in the medication she is given and instead has been taking doses of coconut oil and cinnamon which, according to her, has managed to decrease her blood sugar levels dramatically. She has also started to attend an aqua aerobics class, after her doctor suggested she improve her physical fitness. Whilst she has not been attending this for long, Vivienne is already noticing the difference to her health and general wellbeing this is making.

“I just don't want to mess with the way my body works, if I can sort something without taking medication for it, I will.”

Similarly, Vivienne does not take any significant pain medication for her sciatica since she opted to see a masseuse who provided her with more pain relief than the medication she had previously been on. As such, the only regular medication Vivienne takes is for her heart condition, for which she has a repeat prescription service set up and sees a consultant once every 18 months.

Vivienne is independent and does not see herself as “ill”. Her limited engagement with conventional healthcare systems is due to “their lack of commitment to providing a holistic approach”. She feels that past interactions with doctors have been impersonal and only seen her in the context of the individual condition they are treating her for.

“The doctor I saw for my sciatica didn't listen to me and just fiddled around. But after one appointment with my masseuse the pain just lifted. If I had more money I'd go and see her all the time.”

Instead, Vivienne gets most of her support from a range of close friends and her ex-husband. She has several friends on whom she relies in different ways: some she thinks of as people to have fun with, others she feels she can call when times are tough. Her ex-husband also provides practical support by occasionally picking up her prescriptions and helping her to make small modifications to her furniture to make it easier for her to move around at home.

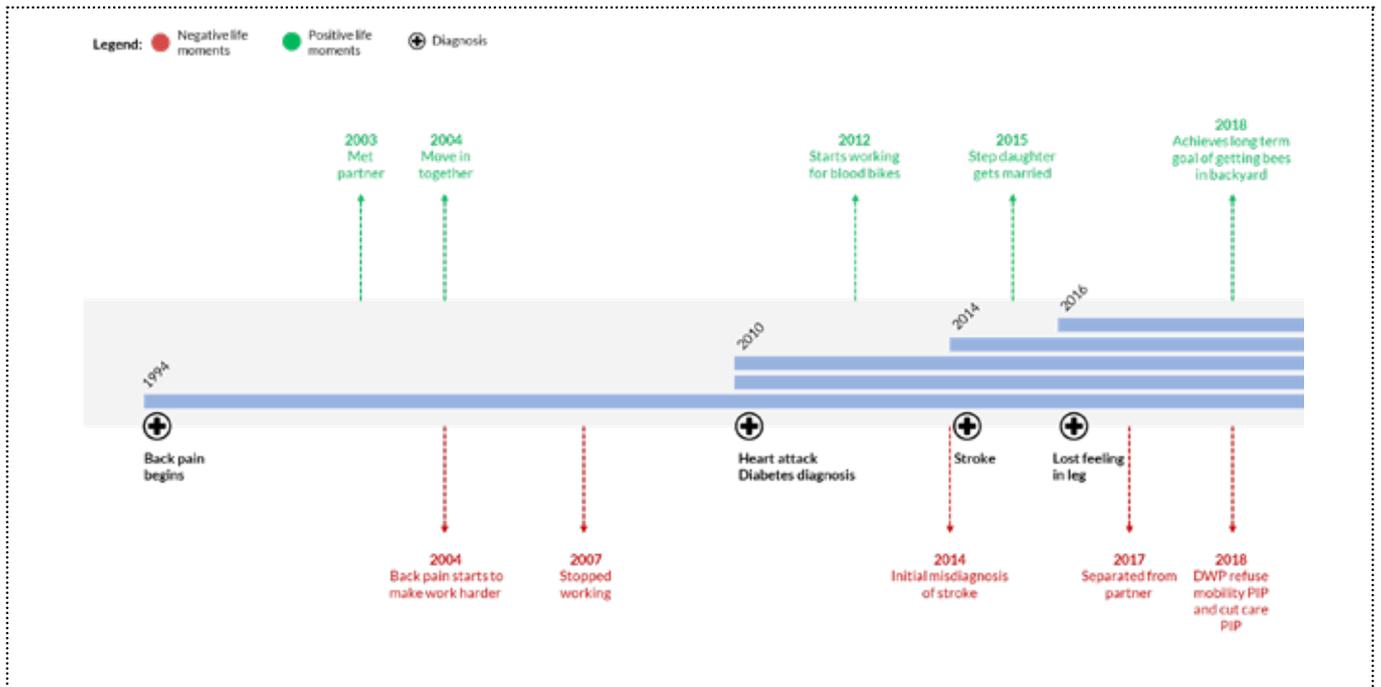
“ The doctor I saw for my sciatica didn't listen to me and just fiddled around. But after one appointment with my masseuse the pain just lifted.



“ It’s a grieving process – my work was a large part of my life and who I was. Saying goodbye to that has been painful.

Keith, 57, Northumberland

MSK, CHD, stroke, type two diabetes, high blood pressure, high cholesterol



Keith lives in a small farm cottage in a rural area of Northumberland with his five dogs, two cats and several chickens. He has lived in the house for 13 years and feels very at home there, despite the dark winters and temperamental broadband connection. Keith’s step-daughter and son-in-law met locally and now live just next door, coming to visit regularly and acting as Keith’s main source of contact with the outside world.

Keith’s health began to deteriorate in 2004, when he started suffering from a “trapped nerve” feeling in his back. Just three years later, he was forced to give up his career after being diagnosed with stenosis of the spine. As a cameraman and sound operator, the pain had started to inhibit him from carrying out the manual tasks essential to his line of work. Keith has struggled to come to terms with leaving the industry, and the lifestyle that came with it, behind him.

In 2010, Keith had a stent fitted and was put on statins after suffering from a heart attack. In the same year, he was diagnosed with type two diabetes and was told he needed to make major changes to his lifestyle. Keith struggled with these additional diagnoses, finding that the movement classes and exercises suggested to him were not designed for an individual with severe back pain. In 2014, Keith had a stroke. This has caused weakness in his left side and difficulty controlling his bladder. In 2016, Keith visited a specialist to assess his back who, during the appointment, manipulated his leg in such a way that Keith has had no feeling in it since then. Keith became increasingly disheartened, feeling as though it was *“just one thing after another”* and struggled to see how things could get better.

His changing health situation put pressure on his relationship with family and friends. He could no longer manage trips to the local pub, and visiting old work colleagues that live further afield became impossible. Indeed, for Keith, living in such a rural area, combined with his mobility issues, has hindered how socially active he can be. In 2016, he and his wife split up after years of relationship difficulties – many of which Keith believes stemmed from his changing health situation.

“My wife wouldn’t leave me alone, she’d be fussing around me and wouldn’t let me get up from my chair...it frustrated the hell out of the both of us.”

Once he was living alone, Keith blocked off the top floor of his house and moved in to three rooms downstairs. He now spends most of his time watching television and chatting to friends on Facebook in the living room, which is cluttered with glyceryl trinitrate sprays, a short-acting formulation that provides rapid relief from chest pain as and when it happens, and old folders with medical information and leaflets, all gathering dust. Keith has had varying levels of support from health care professionals. Whilst the incident in 2016 after the manipulation of his leg left him with limited trust in healthcare professionals, Keith has one GP that he feels understands his situation. Keith will store up several small health issues and compile a list, going to visit his favourite GP every few months to seek help. After talking to him about his health, they will spend a couple of minutes catching up about their favourite music and new albums by bands they follow.

Keith has also taken several steps himself to adapt to his changing health situation. No longer able to ride motorbikes, Keith has found the *“next best thing”* in supporting the Blood Bike charity. Once or twice a month, Keith travels to events to spread the word about the charity and the work that they do. Whilst a day standing outside takes its toll on his body, Keith takes great joy in his work for Blood Bikes and loves that it makes him feel useful.



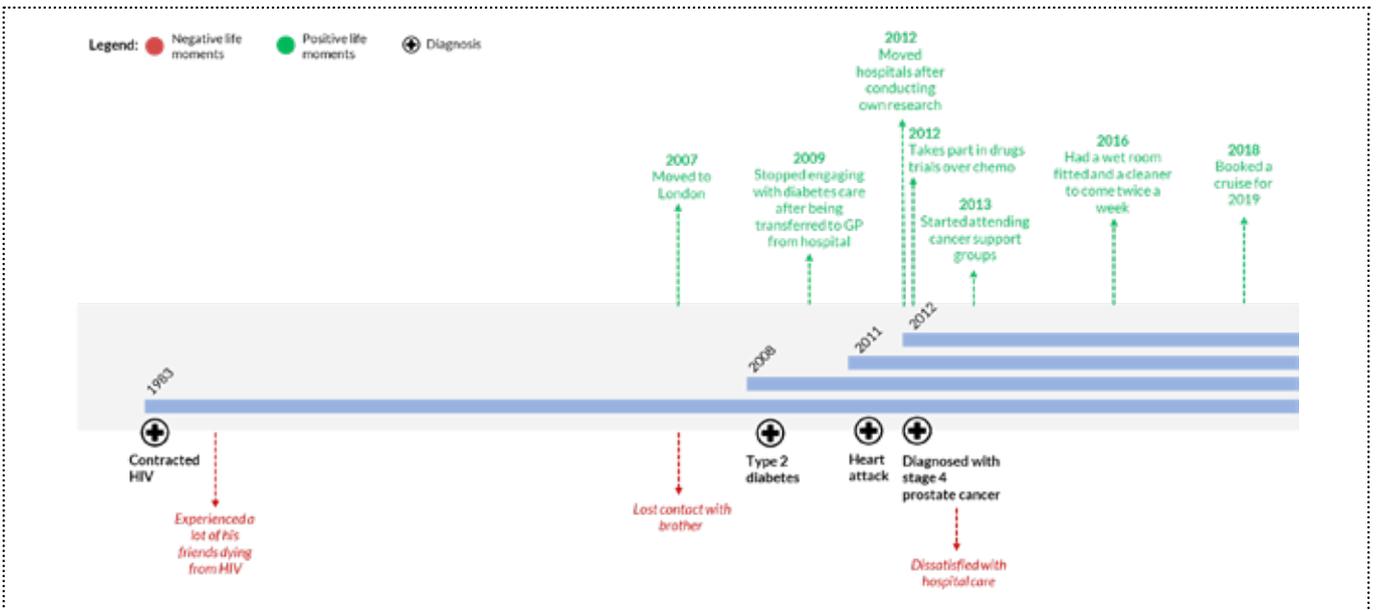
Once he was living alone, Keith blocked off the top floor of his house and moved in to three rooms downstairs.



Godfrey religiously takes a swig of whisky after his medication each morning. Despite not drinking at any other time in the day, he claims that this gives him the ‘get up and go’ to face the day.

Godfrey, 71, Lambeth

Prostate cancer (metastatic), HIV, ischemic heart disease, type two diabetes



Godfrey is a retired factory weaver, who moved to London from Liverpool at the age of 60 in the hope of a fresh start and new lease of life in his later years. He lives in a small council flat in Lambeth with his beloved Jack Russell “Muppet”. Godfrey has spent a large part of his life dealing with health problems after being diagnosed with HIV in 1983. Despite having numerous spells in hospital and losing many of his friends to the disease, Godfrey has “*lived to tell the tale*”.

He was diagnosed with type two diabetes in 2008 and suffered a heart attack in 2011. In 2012, Godfrey was told he had stage four prostate cancer, which has since become metastatic and spread to his bones. Despite having multiple serious health conditions, his attitude towards his health situation has remained positive, he explained that he “*should have died a long time ago*” and that he views his life now as “*bonus years*”. As such, Godfrey takes a reflective approach to his healthcare, critically assessing options available to him and prioritising those that will improve the quality, over the quantity of his life.

After three months of being dissatisfied with the cancer care he was given at one hospital, Godfrey researched other options available to him and approached another hospital to continue his care. Since being under the care of this hospital, he has decided to not undergo chemotherapy and has instead been involved in a number of drugs trials, feeling that these will not limit his quality of life in the same way that chemotherapy would. He also attends prostate cancer support groups, but has asked to receive emails about what the session will involve each week. That way, he explains, he will not waste his time going to sessions aimed at younger men but can attend those he will find useful or uplifting.

By contrast, Godfrey places little emphasis on his diabetes and the medication he takes for this. When he was first diagnosed he went to the hospital for regular check-ups and reviews. However, since being discharged to the care of his GP, he rarely goes to his appointments and does not see them as important. He explained that it was the least significant of his conditions and was not what was “*going to kill me*”, so he did not see it as a priority.

Away from doctors and hospitals, Godfrey has independently sought out support and devised coping mechanisms. After chatting to an elderly neighbour two years ago, Godfrey found out that he could get more help than he had assumed, and went about organising for a wet room to be fitted in his apartment and for a cleaner to come in once a week. Godfrey religiously takes a swig of whisky after his medication each morning. Despite not drinking at any other time in the day, he claims that this gives him the “*get up and go*” to face the day. He also continues to travel, looking into the future of summer 2019 and booking a cruise to visit all the places in the world he hasn't seen yet.



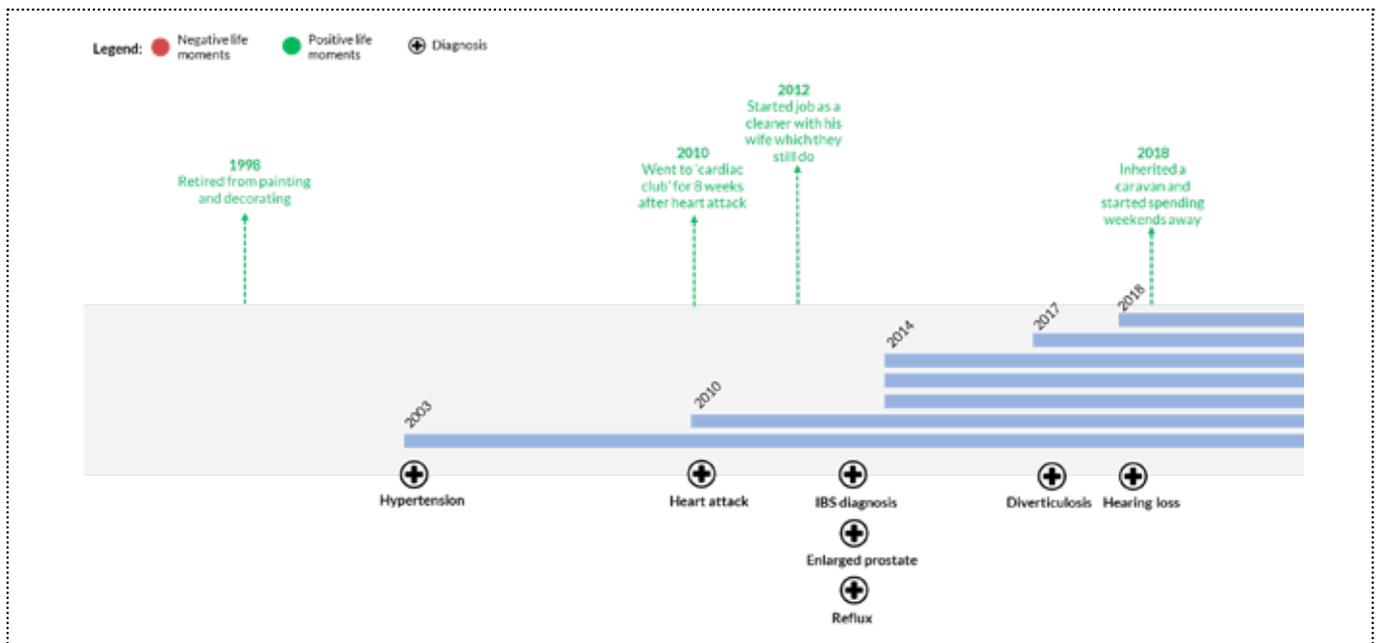
Away from doctors and hospitals, Godfrey has independently sought out support and devised coping mechanisms.



“ I still work because it means I can stay fit, feel useful and gives us the bit of money we need to run the car and remain independent.

Peter, 81, Taunton

Heart attack, high blood pressure, enlarged prostate, atrophic pancreas, reflux, diverticulosis



Peter lives in Taunton with his wife and their small dog. He has lived in Taunton all his life and couldn't imagine living anywhere else. He spent two years in the air force as a young adult during the Suez crisis and spent the rest of his adult life working as a painter-decorator. He gets a lot of enjoyment out of fixing things for his family and DIY. He has two sons with his wife, who are now 59 and 50. He also has seven grandchildren and eight great grandchildren, who are constantly in and out of his house. Peter mainly has acquaintances rather than friends, as he was always "more of a family man".

"I still work because it means I can stay fit, feel useful and gives us the bit of money we need to run the car and remain independent. I've got my family: You can't ask for much more than that."

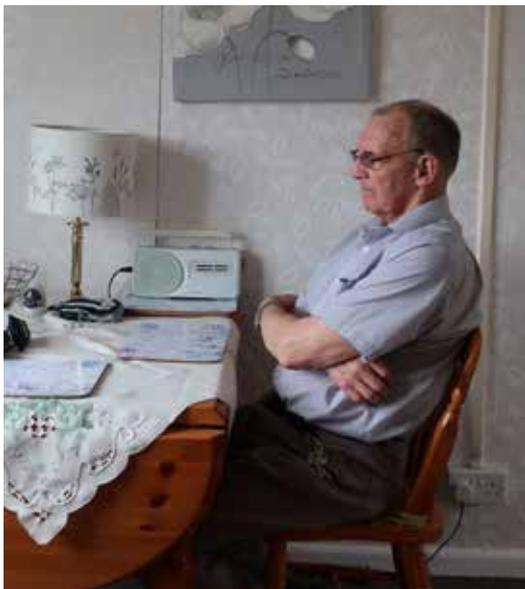
Every weekday morning, Peter and his wife do the 15-minute drive to the local golf club where they are employed as cleaners. They stay for two hours, with Peter cleaning the bottom floor and his wife tackling the top floor. Peter is a great believer in the power of physical activity to maintain good health and of work to give one a sense of purpose. The money they receive goes towards keeping their car running, thus helping them maintain their independence. After work, Peter and his wife do the grocery shopping and go home to help with the kids. They are creatures of habit, but recently had a change to their lifestyles; they were gifted a caravan by a friend and are enjoying taking most weekends away together.

“Most elderly people tend to get up in the morning, turn on the television and just do nothing. They stagnate, instead of thinking to themselves, I must go out for a walk, or something.”

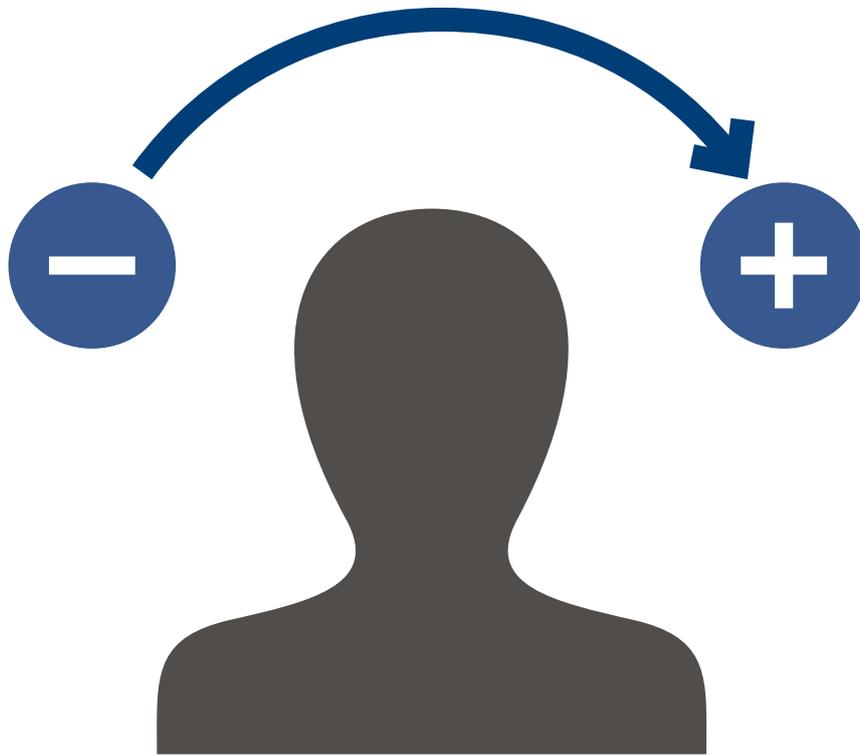
Peter had a heart attack in 2008 after playing cricket. He recovered well, completing ‘cardiac club’ in six weeks rather than the normal eight. He was told to take it easy from then on, to avoid lifting heavy things and take rests when tired. Since the heart attack, Peter has been diagnosed with several more ailments, including hypertension, IBS, an enlarged prostate, reflux and diverticulosis.

“I had to go for an endoscopy and colonoscopy. It was embarrassing.”

About a week prior to the interview, Peter was also fitted with hearing aids. His wife suffers from similar health issues such as diverticulosis and hypertension, and sometimes requires a stick to aid her walking. Peter has a GP whom he has known for many years and whose advice he trusts implicitly. He likes to wait to get appointments with her specifically rather than seeing another GP. Although he doesn’t take a big interest in his illnesses, he might read up about them at the library or get a grandchild to do it. What he does worry about is getting cancer and no longer being around for his great grandchildren. Generally, however, Peter just feels lucky to not be more ill at his age.



“ The only thing I really worry about is the big C taking me before I’m ready. But I think I’ve achieved everything I wanted to. Last year my son took me on holiday and we rode camels. I never thought I’d be the kind of person to ride a camel.



By adapting and developing coping strategies, people are able to **regain some agency over their conditions and their lives.**

How do people adapt to life with multiple conditions?

All of the study participants have ups and downs, better days and worse. They often described their experiences of living with multiple health conditions in terms of what they have ‘lost’ over time, most frequently a loss of mobility and the social connectedness that comes with the ability to get out and about, and engage in social activities.

They also tend to experience an increase in physical pain, and a decrease in mental wellbeing. In many cases people feel stuck, with limited – if any – options.

Living well with any long-term medical condition, more often than not, requires adaptation. While living with multiple long-term conditions often involves a series of physical and mental losses, and can disempower individuals, people do sometimes find their own ways to take control and manage their situation. By adapting and developing coping strategies, people are able to regain some agency over their conditions and their lives.

No single strategy will work for everyone, and an effective adaptation is necessarily tailored to personal specificities and individual requirements. This insight speaks to the value of close collaboration between individuals and the health care professionals they are in regular contact with in devising these strategies.

As will be seen from a closer analysis of the study participants below, there are key ‘transitional moments’ in each person’s experience where appropriate intervention or support can have a significant impact on how these adapting behaviours develop, and the effect they have on someone’s quality of life.

When these moments are missed – as they often are – the effect on people’s health and wellbeing can be dramatic and sometimes irreversible. The reverse, however, is also true: when opportunities are taken to help people adapt during these transitional moments, the long-term outcome can be quite different. The interventions, support or adaptations made at these points in time are likely to inform the patient’s experience from that point on.

The development of effective strategies is about enabling individuals to do well by themselves. Whether through information, aids and adaptation, exercise, organisational skills, or communication with loved ones, people need to be equipped to prepare for and deliver their own adapting strategies successfully. It is important to remember that the development and delivery of such strategies is time consuming and requires effort and energy that many individuals simply cannot give. This is where the health and care system can play an important role, beyond medical interventions, to give individuals agency over their conditions and the support to develop strategies to help maintain their quality of life and potentially slow the progression of further health loss.

In this section the ‘adaptations’ that the study participants had made over time will be explored, as well as the consequences of taking or missing opportunities for intervention, support and adaptation. The opportunities and people’s experiences can be categorised into broad themes that are explored in more detail here, and include: Feeling in control, reducing the ‘health bandwidth’, maintaining meaningful relationships, developing productive relationships with professionals.

Feeling in control

The accumulation of multiple conditions can make people feel as though they have no control over what is happening to them, and like they have little ability to exert any impact upon their health. They often find it difficult to stay on top of monitoring and managing more than one condition.

Some appeared to feel taken over by their ill health, and it was hard for them to know how to respond. Susan described the difficulty of recognising the symptoms of different conditions, and tended to think about them as a single problem:

“It’s all just one big chunk of pain.” Keith found the addition of more health conditions clouded his ability to see ways he could help himself: “You just think, ‘Oh, another thing to add to the list.’”

Others, however, had found opportunities to respond to their accumulating health conditions by taking greater ownership of their health, for example, personalising strategies for self-management, reflecting more on what worked for them and what didn’t, or taking an active interest in their medication.

Of course, there may be factors affecting the extent to which people feel able to take control of their health. Age, for instance, might play a significant role. Anna, the youngest respondent, who was diagnosed with type one diabetes at a young age and experienced excellent paediatric care, had quite high expectations from her care providers and felt very much like she was the expert in her condition. By contrast, Peter, the oldest respondent, displayed a very deferential attitude towards his care provider and expressed disapproval of the idea that people would not take their doctors’ advice. People should feel encouraged and empowered to find personalised ways of managing their conditions, when it is appropriate, but with a recognition that this will look different to different people.

Self-management strategies

Several of the study participants had developed strategies to manage their conditions. Wendy prided herself on her intricate and personalised self-management system. Pinned up on the walls of her house, and in folders in the living room, Wendy had reminders of the things that make her happy, her *“bliss list”*, and the triggers she needs to look out for that may have an impact upon her mental wellbeing. She also has a *“signs and symptoms”* spreadsheet that she completes every day. If the total number of signs and symptoms recorded exceeds five, the auto-sum cell will turn red and this

is a signal to Wendy that she needs to consult with her best friend and with her partner, her ‘team’, to discuss what to do. Although the original inspiration for Wendy’s system was the Wellness Recovery Action Planning (WRAP) – something she learned about through numerous interactions with healthcare professionals, Wendy had taken this inspiration, built something that worked for her, and then added to and adapted it throughout the years. The end result is a group of strategies that are unique to Wendy that she relies on daily to keep a grip on her mental state and to live independently with schizoaffective disorder.

However, coping strategies can sometimes be rendered less effective by the build-up of health problems, with a new condition often making it incredibly hard for the individual to implement previous routines. Two years ago, Wendy was confronted with a real challenge to her self-management; she was involved in a car crash, which caused her serious back pain and leg weakness. Six months later she suffered a nasty fall, breaking her elbow, wrist and several ribs. What followed was a period of serious physical inability.

For a few months Wendy could not shower or bathe without assistance, go up or down stairs, get dressed or get in and out of bed. She described this as one of the lowest periods of her life and noted that the *“situational depression”* she felt from the physical pain and disability was something quite separate from the low periods she experienced as a symptom of schizoaffective disorder. These additional health problems meant Wendy was less able to rely on her tried and tested coping strategies. She was less physically able, for instance, to get outside for 30 minutes a day, which is one of her self-imposed rules to maintain her mental wellbeing. Enough sleep is also crucial for Wendy’s mental health and living in pain made getting a good night’s rest more challenging. Wendy explained that her mental health disorder means her perception of reality is sometimes skewed and this can particularly impact how she experiences the passing of time. She described how during this period it felt to her as though the pain was *“the only thing I knew”*. This was a time in which Wendy was too vulnerable to adapt her coping strategies.

Susan also struggled to adopt self-management strategies when it came to her diet and physical activity, in particular because of the interconnected nature of her conditions. Although she knows that she should exercise and lose weight to improve management of her diabetes she cannot stand for more than five minutes without significant pain. She finds it hard to take ownership of each discrete condition as her experience of them is so interwoven.

She feels attempting to take in to account one condition when trying to manage the symptoms of another too hard, and often concludes trying is futile. If somebody living with persistent pain is struggling to be active, they need outside help which includes tailored support to address their behaviour and beliefs, to develop an approach which works for them.

Directional approach to healthcare

Some people found the best way to feel that they 'own' their treatment and care was by selecting what felt relevant to them, rejecting the options they have no use for and/or seeking alternative treatments. They were often directing and proactive in their approach, in terms of deciding for themselves what would work for them. For Vivienne, sessions with a masseuse are of more value to her than GP appointments because they provide more pain relief for her sciatica. Godfrey reads the weekly email from his prostate cancer group but only attends sessions he feels may be beneficial or relevant to him. After Anna was prescribed thyroxine to treat her newly-diagnosed hypothyroidism without being warned by her GP of the possible side effects of this medication interacting with her insulin intake, and having received no advice from the diabetes team at her hospital, she decided to change her hospital care to a new trust. Anna had been used to "excellent" care in the past when she was seen by a paediatric diabetes specialist and had high expectations. After living with the condition for most of her life she felt that she was the expert when it came to her diabetes management and had the confidence to make a change in her care. Whilst this incident should never have occurred in the first place, it demonstrates that people who are adept at managing their conditions are more likely to reflect on what is best for them and their situation and make informed decisions based on this. Of course, it can take a lot of energy, mentally and physically, to be able to take a positive and proactive approach to managing health.

Many of the respondents were reliant on a multitude of medications but displayed varying levels of comprehension and differing attitudes towards adherence and control.

Some were 'coping' with being prescribed multiple medications by disengaging from them. Susan, for example, did not comprehend exactly what her medications did or how they were supposed to help her, and did not particularly appear to want to know. Keith, by comparison, could list the 12 types of tablet he was taking and what each was for. Susan and her husband felt inundated with side effects leaflets; they had taken to throwing these away, and instead looking up potential side effects or interactions on



'Drugs.com'. Susan is also happier for her husband to deal with her medication on her behalf. He picks up their prescriptions once a month, divides them in to plastic boxes for morning and evening each day and then stacks them up next to each other in the kitchen so they can see at a glance if one of them hasn't taken their pills. Peter could not easily recall the four specific medications he was on or what they were supposed to do and was in fact quite vague about the illnesses he had. He was very deferential to his doctor and disapproved of people who do not listen to clinicians' advice.

Several study participants displayed a selective attitude to their medication, usually based on an attempt to weigh up the benefits against the side effects. Matilda said she was prescribed so many tablets by her doctor that if she took them all, she would spend all day asleep. She worried that if she spent all day asleep, she would put on more weight and it would be even more difficult to move around. As a result, she did not take all of her medication. Matilda also displayed a somewhat resistant attitude towards her HIV medication in particular; she said she often only took five out of seven of her tablets a week, saying both that she 'forgot' to take it and that she purposefully avoided thinking about being HIV positive. Matilda was resentful of the 'adherence nurse' at the HIV clinic and the many medications she has been prescribed for a very long time. This seemed to tie in with a general distrust of healthcare and the acceptance that she would always be ill, no matter what medication she took. Matilda had also developed a 'detox' strategy for her morphine prescription, trying to periodically ween herself off it so that her tolerance did not increase.

Wendy chooses to manage the psychotic symptoms associated with schizoaffective disorder through "lifestyle" rather than medication because she is no longer willing to take anti-psychotic medication,



believing that it *“dulls her out”* and affects her quality of life. Wendy knows people who passively take their prescribed medication, despite *“hideous side effects”*, and feels she is different because she has the confidence and the know-how about her own health management to abstain. After much discussion, her doctor allowed her to take anti-psychotic medication when she felt she needed it. She keeps this *“emergency”* medication in her house, and finds she needs to take it three or four times a year, when she is having serious periods of mental distress.

For Godfrey, at 71, chemotherapy was not worth risking losing his quality of life. Instead he has chosen to partake in many medical trials and generally takes all the medication he is prescribed without issue. The only *“medicine”* he seemed to notice a difference with, however, was the self-prescribed glug of whiskey he drank every morning.



Reducing the ‘health bandwidth’

Living with multiple health conditions can result in the loss of some aspects of life that previously gave great meaning and purpose. As the focus on symptoms,

medications and appointments takes hold, it becomes harder for individuals to make room for other things in their life. Health – or ill health – takes up an increasing amount of people’s ‘bandwidth’, squeezing out time and energy for other activities. In these circumstances, people often default to thinking about what they can *“no longer do”*.

Finding ways to maintain or rediscover activities and enthusiasms apart from their conditions helped several of the research participants feel they were coping better. Reducing the ‘bandwidth’ that health took up and replacing it with positive alternatives gave their lives meaning beyond their health.

Daily routine

Daily life with multiple health conditions can easily become repetitive, with an overwhelming focus on condition, symptom management and administration of healthcare and beyond. Those who found ways in which they could make daily tasks easier and weave variation into their day to day activities, were able to reduce the amount of bandwidth taken up by health.

It was common for the study participants to have home adaptations and tools to adjust to their new health situation and make daily life easier. For some, this meant major house adaptations. For example, Godfrey had a wet room fitted by *“a man from the council”* after his neighbour told him they’d managed to get one. He was full of praise for the wet room and said it had made his life significantly easier. Vivienne also had a wet room with a plastic chair in her shower. It was fitted prior to her moving in but *“if it hadn’t been it would have been one of the first things I did”*.

More commonly, people used smaller, personal aids or digital support. Keith had been given *“grabbers”* by his occupational therapist to help him put his socks on or pick things up from the floor. He also had handles fitted outside his front door to help him up

his stairs. Susan had makeshift wheels screwed to the bottom of her coffee tables so that they could be easily manoeuvred. Anna used her phone to help her manage her conditions, setting alarms to remind her to take her medication and frequently visiting diabetes forums to look for advice.

For others, there was a need for more help from social care. Wendy described how, after her fall, she has found it difficult to do the smaller things in life that could aid her wellbeing such as cooking for herself; with the pain in her legs, she can't always manage to reach down to her cooker. She expressed the desire for someone to help her with things such as going outside for a walk, but she didn't know where to look or how to access this type of help. Matilda too expressed a desire for adaptations in her home as she finds it particularly difficult to go up the stairs. She is also reliant on her housemate for getting out of bed and starting her day every morning. She did not mention having had any interactions with social care organisations to address these issues which are having a significant impact on her daily life.

Interviewing people in their own homes made it easy to see just how important pets were to many of the respondents. For seven out of the ten respondents, pets provided companionship and therapeutic benefits. Respondents spoke about how having an animal to look after gave structure and purpose to their daily routine which may otherwise have been lacking.

Godfrey has had dogs for years, and got his beloved Jack Russell "Muppet" from a rescue centre soon after his diagnosis with prostate cancer. Since then, she has become his "best friend" and is clearly the source of a great deal of joy in his life. Godfrey looks forward to his afternoon walk around the park with Muppet, getting fresh air and often pausing to sit on a bench and chat to other dog walkers. Similarly, both Matilda and Peter said their pet dogs were often the reason they got up in the morning. For Matilda, taking her dog on a walk was often the only time she would leave the house or physically strain herself throughout the day. Knowing that they had the responsibility of feeding and looking after their pets sometimes gave these respondents a purpose and routine that may otherwise have been lost amid the focus on health conditions.

"She has to be got out for a walk, one way or another. Luckily, I'm quite close to the edge of the field here so I can hobble out and throw a ball for her for a bit. Then I need to come in and take more medication."

For some respondents, cooking and cleaning – activities that were part of their daily routine – became difficult and would depend on how they felt that day. For example, when Susan's husband is out at work and she is on her own, she is often in too much pain to cook. This means she often misses meals and struggles to eat healthily. Similarly, Susan struggles to clean as much as she would like to, and as a result, she feels her house is 'cluttered' and doesn't enjoy spending time there as much as she used to. Help with cooking and cleaning are therefore two things that may be beneficial to Susan.

Work

Several respondents adapted their employment to enable them to continue to work despite their changing health situations. The most notable example was Vivienne, who found herself unable to cope with her high-powered, demanding career in consultancy after becoming ill. Instead, she became a teacher and mentor to young people looking for work. She found that, in this line of work, she was still able to practise the training and support elements of her old job without the pressure and long hours she had previously. Continuing her work also enabled her to remain future-focused, seeing her current job as a step in the right direction to getting her career back to what it was before she got ill.

Similarly, Peter worked as a painter and decorator before his retirement, but has since taken up a role as a cleaner at a local golf club with his wife. They travel to the club each morning, where they split up and clean a floor each. While Peter does find the work physically demanding, the extra income and purpose it gives him and his wife helps them extend their lives outside of his health conditions. However, for the majority of people in our sample, it was not possible to continue working in this way. For some this was because their illness meant that they could no longer do their job, but for others it was their work who were unable to support them to continue working.

In general, once respondents became ill, there was a lack of encouragement to continue working in some form or change to a more suitable job. Although programmes exist,⁹ many were unaware of them.

Hobbies

For many people living with long term health conditions, keeping up with existing hobbies and developing new interests can seem a low priority and an unrealistic ambition. As people begin to work less, the line between work and free time can become blurred, and people are often less inclined to make plans with the time they have available to them.

However, some of the study participants were able to find new interests or adapt previous hobbies to enable them to continue pursuing these in the face of their changing health situation.

Keith was devastated when his back condition and leg numbness stopped him from riding motorbikes. A self-confessed “*speed-junkie*”, Keith spent years investing in new cars and bikes, each one faster than the last. Many of his friends were also motorbike riders so this shared interest was the foundation of his social life. Determined not to leave motorbikes behind entirely, Keith became involved with the Northumbria Blood Bikes which fund motorbikes to transport blood urgently between hospitals and air ambulances. Once or twice a month, Keith travels to fairs and events in the local area to man the stall for the charity, talking to members of the public and raising donations. Despite this taking its toll on him physically, Keith feels as though it is the “*next best thing*” to riding motorbikes, coming away feeling upbeat and as though he has been useful.

Vivienne’s changing health situation also encouraged her to take up a new hobby; after it was mentioned to her by her doctor, she decided to investigate aqua aerobics classes in her local area. She now attends a class at least one afternoon a week. Although this was suggested to improve her physical health, she has found it has also made a difference to her general wellbeing, enjoying the variation it brings and new people she has met through it.

Maintaining meaningful relationships

As health takes up an increasing portion of somebody’s time, or immobility and pain start to make socialising more difficult, relationships can dwindle. If a person’s mood is low, or they feel they have nothing to talk about, they are also less likely to seek out people to talk to or spend time with. Close relationships can become strained or at least significantly altered by a loss of mobility or independence. People living with multiple health conditions often see their social networks shrink and, at worst, can face real social isolation.

Those seen to be coping better could adapt their social networks to suit their new health conditions. Some made new friends, some connected with old ones. Others had very supportive family members who diminished any feelings of being a burden. Some branched out, for example, Megan volunteers at a mental health café, and helping other people cope through art has become her own way of coping.

Supporting independence

For Wendy, her boyfriend and her best friend (who is also an ex-partner) are her support team. They know everything about her mental health situation and are on hand to help her whenever she needs them. Wendy also approaches any new personal relationship with complete upfront honesty about her mental health.

“If I think somebody’s going to be a part of my life, it’s better that they know straight away.”

She has used this strategy when recently starting a university course. She wanted to let her new classmates know from the beginning that her behaviour may be erratic at times. She feels fortunate to be part of a friendly local community, members of which have at times helped her get home when she was in a poor mental state.

“They know I’m a little bit different.”

Wendy prides herself on her ability to live independently with schizoaffective disorder. When she became physically impaired, however, it meant having to rely on her friends and family beyond a point she was comfortable with. The perception of being especially burdensome was an intense strain on Wendy.

Susan described her increased dependency on her husband, a result of losing her mobility. Susan’s husband effectively acts as her carer now, despite suffering from multiple conditions himself, including diabetes (type two), hypertension, enlarged prostate, diverticulosis, brittle bones, depression and ventricular fibrillation. Susan used to socialise regularly with her colleagues but now most days Susan cannot leave the house because the pain from her osteoarthritis is unbearable. On top of this, Susan, at 53 years old, did not want her old friends to see how much her health deteriorated.

By contrast, when Keith stopped working, he kept in contact with a friend from the industry. They bonded over a shared difficulty as they both experience back pain, and Keith appreciates having someone who is in a similar situation to talk to. Nevertheless, he lives in an extremely rural area and is now entirely dependent upon his son-in-law for getting out of the house, for example for going shopping and to health appointments. He also explained that he feels he has to hide how he is really feeling from his family in order to protect them, and that he could only really be open with his friends, but he does not get to see them as much.

Maintaining and expanding social networks

There was evidence of coping with diminishing health by maintaining and improving personal networks. For Peter, deteriorating health meant increasing the time he spent on personal relationships. As Peter has got older, and his ailments have worsened, being there for his infant great grand-children has become his priority. He believes that this is what gives him purpose in life and is the reason he tries to keep fit and active. Peter also thinks ageing has made him more prudent about how time is spent; he and his wife always try to keep their weekends free to spend time just with each other.

Anna is very close to her family and she has leaned on them in times of poor health. When she was diagnosed with hypothyroidism, she went straight to her mother, who suffers from the same condition, for advice. She also received advice from her stepfather, who is a retired GP. Beyond her immediate social network, Anna finds reading and posting on the Diabetes UK forum helps her to manage her health. People on the forum swap practical advice and provide announcements about new treatments or new types of insulins, and which CCGs are doing what. More specifically, after Anna was left feeling confused and alone when, unbeknownst to her, her new prescribed medication (thyroxine) was increasing her blood sugar, she found the answers to her questions on a diabetes + hypothyroidism sub-thread.

“If I hadn’t found people on the forum who had said it had happened to them too, I would have been really worried. I didn’t know what to do...because I saw that, it calmed me down a bit.”

Anna checks her forum app multiple times a day. For her, it is not only a way of helping to manage her condition but an outlet where she can vent her frustrations and connect with people who feel similarly. As a young woman, Anna sometimes feels different to her friends and can feel isolated; connecting with other type one diabetics helps her feel less alone.

“It does get me down. I have a much lower life expectancy than my friends. Some days I just think ‘I don’t want to have this anymore’. I want to eat what I want and not worry about it.”



Of course, not everyone will be as comfortable as Anna in using technology as a way of engaging socially. In addition, not everyone necessarily wants to connect more with others who suffer the same conditions. For many years Matilda was heavily involved with HIV patients’ support groups, both attending and helping to organise them, but she decided to remove herself from this “scene” because she found HIV became all that her life was about. Nevertheless, the point remains that there are potential connections to be made through health, and in the digital world finding new social networks and reaching out to others can be easier than ever. Additionally, Matilda was reflecting on her situation and whether it was really helping or hindering her. This kind of selective approach may be important in helping others to take greater ownership of their health.

When someone’s health deteriorates, it can lead, in the worst cases, towards social isolation. Some of the people we spoke to struggled to maintain friendships or even relationships with family as they became more ill. This was particularly true when their mobility decreased and they struggled to leave their home, or when their mental health worsened. For those who were doggedly trying to maintain social networks, they more proactively used their situation to build new connections around their health, rather than seeing it as an impediment.



Developing productive relationships with professionals

The relationships between people living with multiple long-term health conditions and their healthcare professionals are complex and varied. This is no surprise, given the many appointments, professionals and services these individuals interact with on a regular basis, and the complexity of the issues they are receiving support for.

There was an overwhelming sense from respondents that they felt healthcare professionals only got a snapshot of their health situation, focusing on the one condition or symptom they were addressing in that moment. As such, respondents felt as though their healthcare professionals were not looking at their health in the context of their multiple conditions and varied health histories. To address this complexity, many of the respondents had developed techniques, strategies and mindsets to enable them to get the most out of their interactions with healthcare professionals.

Building relationships

For some respondents, forming significant and personalised relationships with their healthcare professionals was a priority and, indeed, a necessity to get the most out of their interactions with them. Without such relationships, respondents found themselves frustrated and de-motivated to take steps to manage their health situations.

After being given a misdiagnosis for his stroke in 2014, Keith felt a lack of trust in healthcare professionals and little motivation to attend appointments or check-ups. However, when Keith

started seeing a new GP at his local practice, things changed. Keith felt as though this GP *“really made time for him”* and, as a result, began to book all his regular appointments with this professional. He discovered they had the same music tastes, and Keith would often use this common ground as a way of providing small talk at the beginning of an appointment, easing him into being able to talk about more sensitive issues. Whenever he can, Keith now books appointments with this GP as he has become confident that the GP will know the context of all of his conditions and will put him at ease in the room.

“I store up my problems and go to see my favourite GP once the list gets long enough... we talk about our favourite bands together.”

Vivienne has chosen to reduce her contact with doctors and consultants, after feeling they did not provide a *“well rounded”* support strategy. Instead, she has built up relationships with more alternative practitioners, such as nutritionists and masseurs. Vivienne feels as though she gains more holistic support from these individuals, which she felt was lacking in previous interactions with the healthcare service. She sees her interactions with care professionals as a *“working relationship”*, expecting reciprocal respect and effort from both parties. By seeing the relationships as such, she feels more motivated to take control of her conditions and treatments.

Health and care hacks

As well as building more personalised relationships with their healthcare professionals, many of the respondents had built up a range of more practical *“hacks”* for getting the most out of these interactions. It was observed that respondents would *“store up”* a number of issues they were struggling with,

going to see their GP once this list had reached a certain length or became more urgent. The reasons respondents gave for doing this were twofold: having fewer appointments made them feel less as though they were “*hassling*” their doctors, decreasing the sense of being a burden that many people living with multiple long-term health conditions struggle with.

In addition, respondents felt as though seeking help for several issues at the same time meant that they were more likely to receive help and support that catered for the fact they were living with multiple health conditions.

For Keith, a major frustration in his healthcare was that “*doctors didn’t seem to talk to one another*” and he felt he was constantly having to explain his situation to new healthcare professionals. Storing up several issues before making a visit to his GP gave him the confidence that the doctor would look at his whole health situation rather than just one of his conditions.

“There are two doctors who I have seen more than others but, on the whole, I see someone different every time. You get cycled in and out. It means every time I go in I have to tell the same story.”

However, less frequent appointments also meant that respondents felt pressure to make the most of them and ensure they spoke about everything they needed to at that time. Different strategies for dealing with this were observed, with many respondents taking lists about things they wanted to discuss with their doctor that they had made in the days coming up to their appointment. In addition, people often went accompanied to their appointments. Susan and her husband made a point of seeing the same GP and booking back to back appointments, ensuring they had adequate time to discuss what they wanted and to offer support to one another in the room. After struggling to remember his appointments, Paul started taking his sister along to them with him. He said that not only was he more likely to go to the appointments, but his sister helped him to remember what he wanted to discuss and offered moral support when talking about more sensitive issues to his doctor.

“I don’t want to shy away from telling the truth about how I’m feeling, having my sister there helps me with being more open.”

Investigative mindset

Importantly, developing strategies such as these was not something that was seen across all respondents. In some cases, seeking out new healthcare support rather than adapting current relationships was more desirable. One such example of this was Godfrey, who struggled to trust the cancer specialists he was

seeing at hospital. This began during his process of diagnosis, when Godfrey felt as though doctors were not being honest with him about the potential seriousness of his symptoms.

“Right from the outset, I knew it was cancer. I kept saying ‘Just tell me if it’s cancer’ but they didn’t respond, they kept telling me not to worry.”

Even after his diagnosis, Godfrey continued to struggle in the relationships with the doctors and nurses he was seeing, finding that there was a lack of continuity and understanding of his other health conditions. As a result, Godfrey took it upon himself to research other hospitals in London on the internet and talking to other patients that he knew. He came across the “*prostate team*” at Guy’s and St Thomas’ hospital and asked to be referred. He is much happier with the care he receives now, although he worries about others who may not have had the “*same idea*” to look elsewhere for better care. Godfrey explained how living much of his life interacting with healthcare professionals had taught him a lot about what he wanted from his health professionals, and that this had coloured his current expectations.

“There was this one doctor who everyone wanted to see. He was gentle and kind, but he was honest. He would do all he could for you, but when he couldn’t do any more he’d tell you exactly how long you had left and what to expect. In a time when no one really knew what was happening, this was a blessing.”

The ways in which people living with multiple long-term conditions adapt to their changing health situations are well thought-out, varied and, in many cases, inspirational. From small changes like using grabbers and joining Facebook support groups, to making big decisions to move hospitals or decline medication, these coping strategies have a profound impact on people’s lives. They can play a role in reducing impact of the loss, pain, immobility and social disconnect that often characterise “*ill-health*”, and enable people to take control of their situations. It is, however, important to remember that development of coping strategies is time consuming and requires effort and energy that not everyone is able to give. It is also important to consider how the health and social care system can best support development of these strategies for all people living with multiple health conditions, and if there are opportunities for this support to be given prior to people developing a second or third condition, or further losses in their ability to do things around the home or at work.

What support do people need?

As outlined in the previous chapter, people have many ways of adapting their lives and developing strategies to help them cope with managing multiple long-term health conditions. In many cases, these adaptations and strategies were developed to deal with the loss of good health to date and to prevent further loss. Some people, however, found themselves in circumstances that made it more difficult to adapt or develop strategies, often leading them to experience further challenges.

While these circumstances of course differ from person to person, and may be affected by age, gender, socioeconomic background and living situation, there are certain experiences that are seen to make managing multiple long-term conditions more difficult. These include reduction in mobility, chronic pain, shrinking social networks, no longer being able to work, and lower mental wellbeing.

These experiences are not predictable as such, but are widespread and can have serious consequences. Efforts to reduce – or ideally prevent – these experiences are likely to have a beneficial effect. Supporting people to take control of their health, recognising mental wellbeing, helping prevent loss of mobility, encouraging critical reflection on support and clarifying how the system works would all help lead to improved outcomes.

At certain ‘transitional moments’, such support – or its absence – can have a life-changing effect. However, it is often not possible to identify such moments without the benefit of hindsight. Instead, if every interaction with someone with multiple conditions is seen as an opportunity to do one or more of these things, the potential to improve outcomes and create conditions for greater success in adapting are greatly increased.

Ideally, these opportunities would be seized by professionals before someone is diagnosed with multiple conditions, i.e. at every single interaction, so that everyone has the support needed to reduce the likelihood that circumstances occur which make managing more difficult.



Promoting mobility

One of the biggest factors exerting an influence on the experience of multiple health conditions was mobility. Losing mobility made it a lot harder for people to adapt and could result in them losing work, becoming dependent on others for daily tasks and having a significant impact on their self-image and mental wellbeing.

The extent to which somebody was still mobile seemed to be strongly correlated with how able they were to face other challenges. Godfrey, for example, was still mobile despite some other significant health challenges, and his ability to keep his independence meant he was looking forward to going on a cruise later this year, and still got out every day to walk his dog.

People who were less mobile often found it more difficult to adapt to life with multiple conditions or to develop strategies to lessen their impact. This was heightened by the fact that loss of mobility frequently coincided with pain and/poorer mental wellbeing.

Matilda has made significant changes in her life to cope with the loss of work, such as finding new hobbies and ways to fill her time, but what she really misses is being able to go for a walk spontaneously. This is an area in which she felt she had no ability to make changes. She did have a mobility scooter, but it was taken away from her when her benefits payments changed, and it wasn't very suitable for her small cottage in the first place. She also had difficulty going upstairs, but had not been offered social care

provisions for aids and adaptations around the house. Mobility is the most significant challenge Matilda faces and she feels immobility prevents her from making other adaptations in her life.

Key question: How can the maintenance of mobility be made into a priority and how can better support be provided for those who have lost mobility to preserve their independence?

Personal, empowering support

Across all areas of adaptation, professional support that was empowering and promoted independence enabled people to make successful changes. Empowerment looks and feels different for different people, and the degree of responsibility people desired to take for their own health varied. Nonetheless, people who were encouraged to take ownership of their own health while still having access to professional and informal support were more likely to develop personalised and sustainable coping strategies.

Wendy, for example, personalised the strategies she had learned from interactions with mental health support services. Vivienne's decision to take up aqua aerobics was triggered by her GP suggesting she find herself a low impact activity to help manage her diabetes. It was Vivienne, however, who was responsible for finding a class that suited her and is now completely independent in attending her aqua class and seeing the benefits she is gaining. As such, Vivienne has ownership of this activity and does

not associate it with her health issues or doctor's suggestions. For someone who does not want to see themselves as "ill", this encouragement to find something that works for her has enabled Vivienne to make significant adaptations to her lifestyle and to see the improvements to her health and wellbeing without having to rely heavily on her GP.

However, when a person's relationship with a health or social care professional was characterised by reliance or dependence, it was harder for them to make positive changes to cope with their conditions. People whose interactions with professionals were like this from the start, who were not encouraged to reflect on their own needs nor to try to test and develop new strategies, were less successful in adapting to their conditions over time.

Susan, for example, has been seeing the same GP for years and would always rather see that doctor, often having to wait longer for an appointment because of this. Her GP was one of the people she saw most in her life and she rarely sought advice and support from others. Even when she did see specialists or consultants, she would book an appointment with her GP to go over what had happened and for him to tell her what progress had been made. While close and trusting relationships with GPs can be beneficial, over reliance and dependence on one particular healthcare professional often stifles the development of further support mechanisms and a person's ownership of their conditions.

Key question: How can all relationships with health and social care professionals promote independence and encourage personal action? How can health and social care professionals ensure they are identifying barriers to being independent? E.g. inability to use the toilet/bath. How can health and social care professionals move away from the language of 'multimorbidity' and ensure that patients feel motivated to make the most of the support that is relevant to their situation? How can health and social care professionals be supported to sign-post to other services that might improve quality of life and promote independence? e.g. local authority provision of aids and adaptations.

Recognising mental wellbeing

The cumulative effect of multiple health conditions had a significant and discernible impact on mental wellbeing, even in the absence of diagnosed mental health conditions. This was particularly the case when people were living in pain, had reduced mobility or were socially isolated. People whose health professionals acknowledged the importance of

mental wellbeing and were given support were often better able to carve out the 'bandwidth' to maintain a wider focus on lifestyle, hobbies and relationships.

Megan's GP has been very supportive over her mental health conditions, and suggested she see a therapist as well as taking her prescribed medication. She now sees a Lacanian therapist, whom she chose because of their focus on self-help rather than 'change' that she feels other therapies are geared towards. Her GP also suggested she attend mental health cafés to meet new people and share experiences.

Despite being a significant factor in many of the study participants' lives, mental wellbeing was not often regularly discussed or reflected on by health or social care professionals. Keith had been feeling low for months, and his step daughter and son-in-law tried to persuade him to talk to a doctor about how he felt. However, Keith did not feel comfortable talking about this with his GP, worrying that it would be blown out of proportion and that a mental health diagnosis would just be "*another thing to add to the list*". Susan enjoyed making collages and being creative but struggled to keep sight of why she was pursuing a hobby and "*what the point of it all is*". However, she did not often share these feelings with those around her. For both of them, the lack of discussion and support surrounding their mental wellbeing was detrimental to their ability to live well with multiple conditions.

Key question: How can all health and social care professionals more regularly check in on service users' mental wellbeing to ensure they don't miss opportunities to signpost additional support? What support can be provided to improve mental wellbeing?



Informal support to maintain quality of life

For the majority of respondents, a strong and reliable network of family and friends was critical to adapting maintain a good quality of life and develop strategies to overcome practical hurdles.

Keith's close relationship with his son-in-law provided both practical and motivational support for adaptation. On days when Keith was feeling low, his son-in-law would encourage him to visit the pub to see his friends and, once Keith agreed, could also drive and drop him off in town. Without this encouragement and support, Keith felt that he was much less likely to find ways to manage his low mood day-to-day. Similarly, despite beginning to struggle physically, Godfrey had been able to continue going on cruises thanks to a younger friend of his that accompanied him on his trips abroad. For Paul too, the unwavering support of his family has been crucial in managing his multiple health conditions.

Aside from family and friends, support from wider social networks was also significant in helping people make changes to improve their experiences of life. For Anna, this came in the form of an online forum that she visited after her diagnosis with hypothyroidism. Here she found a network of people in similar situations with whom she could share her experiences at the touch of a button. She also first learned about the Libre sensor on this forum, a blood monitoring sensor which Anna has found to improve her ability to manage her diabetes significantly.

People with weaker networks or less everyday support were far less able to continue making the most of their lives beyond their health situation. Susan was estranged from members of her family and had lost a lot of friends since living with multiple health conditions. Once she had lost this network, her low self-esteem was part of what held her back from reaching out to others.

In addition, relying heavily on informal networks might risk complacency, or might be detrimental to the health or quality of life of the individual or their carer. Susan relies heavily on her husband for practical support, who also struggles with managing his own multiple health conditions. Her husband has helped her to make small modifications around the house that help her to do things like reach something far away. Although something as small as this could make a significant impact on Susan's life, it is possible that a more significant improvement could be made if she had help from social care organisations making adaptations around her house.

Key questions: How can we consistently ensure people are building or developing informal networks that facilitate higher quality of life day-to-day? Can people be persuaded to focus less on social interactions they have lost and more on ones they stand to gain?

Working out what works

Those who reflected on what worked for them and what didn't, in terms of the support they received and the strategies they developed themselves, were more able to make changes so that they better met their needs.

Godfrey, for instance, researched new drug trials and options available to him and received emails about weekly support groups. He engaged and actively chose what was relevant to his needs and what he wanted to take part in – and ignored the rest.

If health and social care professionals more often worked together to identify what support could be 'tried', and later discussed how well it was working and what more could be done, the results would likely be even more effective.

As discussed in the previous chapter, Wendy took inspiration from the strategies she has learned from healthcare professionals and developed an intricate self-management system that is based on her personal needs and fits in with her day-to-day life.

But Wendy's story also demonstrated just how critical it is to reassess needs when circumstances change, which can happen unexpectedly.

Wendy's self-management strategies were put to the test when she suffered a fall and her physical needs increased. Despite the fact that Wendy was seeing a physiotherapist on and off during this time, and had a close relationship with her GP who was aware of her mental health condition, there was no reassessment made, by Wendy or by the healthcare professionals involved in her care, about how her needs had changed. This significantly hindered Wendy's ability to adapt and cope. While Wendy eventually got her coping strategies back on track, she did suffer considerably during this time. Someone who was less reflective about their needs could have had even more difficulty.

Key questions: How can people be prompted and supported to take control of the support available to them and engage with and explore alternative options as necessary? How can holistic conversations, assessment and care planning happen at key points be ensured?



Clarity on how to work with the system

People we spoke to were often given a large volume of information and advice about their conditions and treatment, much of which was complex. Those who wanted a sense of ownership of their conditions and their interactions with the health and social care systems were helped by clarity of information and an understanding of which professional services could provide the best support for them.

The most prominent examples of this were around prescriptions and medication. Keith was taking 12 types of medication each day, and had been given clear and thorough instructions from his pharmacist about what each tablet was for and the possible side effects. While his GP did not have time to give Keith these thorough explanations, he was pleasantly surprised to find that he could get this information elsewhere.

By contrast, while Anna is extremely knowledgeable about diabetes and how insulin affects her, when she was prescribed thyroxine for her new condition she did not check the leaflet that was included with the medication. The medicine interacted with her insulin and resulted in her blood sugar levels rising. In this example the doctor made a mistake; this medication should not have been prescribed, or at least not without a clear discussion of possible side effects. Anna was not given clear enough information about what medication she was being given, or where to find out more about it, highlighting the need for doctors to provide greater clarity of where their responsibilities end and patients' begin. If people were encouraged to take a greater interest in their own medications and treatments, then they might be

better able to notice if a doctor did make a mistake such as not discussing possible side effects and interactions, as well as being better informed about what to do if something does go wrong. For others, confusion over how to engage with the system, and which professionals should or could be approached for different symptoms or non-health related issues, impeded easier management of conditions. Susan, for instance, did not feel confident that she could mention her other conditions when talking to specific consultants:

“They are specialists, they are purely for cardiothoracics so I would need to see the doctor who deals with bones and joints about my other problems.”

She thought there might be some exceptions, for example, “if my arthritis caused breathlessness then maybe I would tell them about it,” but otherwise did not know if it was appropriate to bring up what were significant issues for her. It may be that Susan misses out on better care because she does not feel she is able to discuss her health holistically with healthcare professionals.

Other respondents spoke about wanting more support for non-clinical difficulties they were facing, such as relationships with those close to them or wanting to find new hobbies. There seemed to be a sense of confusion among both respondents and their healthcare professionals about where the responsibility of one professional ended and another began.

Key question: How can it be ensured that people feel clear about what they can ask and expect of the health and social care system?



So, I'll have to take a tablet every day for the rest of my life to control my thyroid. Frankly, that's nothing compared to diabetes.

Anna, 24



Principles for a holistic approach

Over time, there are numerous opportunities to influence – directly or indirectly – the experience of someone living with multiple long-term conditions.

Many of these opportunities can be taken at any stage – it is never too late to improve the support offered, take a fresh approach or encourage a different activity or attitude that could improve the conditions for an improved outcome or experience. It is also never too early; mental health in particular is often the last thing considered by both the individual and the system supporting them even though mental resilience can be seen to improve people's lives overall, not just in moments of crisis. In addition, even small interventions can make a huge difference.

To ensure opportunities are not missed, while also maximising the chance of improving the experience at any stage, it may be helpful to consider all interactions with someone with several long-term conditions as an opportunity to apply a set of principles intended to increase the likelihood of supporting the person to live the best life possible.

Underpinning all of these principles is the fundamental need to consider lives and experiences as holistically as possible – taking account of physical health, mental wellbeing and quality of life.

It is important to stress that these principles are not reserved only for interactions with people who have several long-term conditions. While the intersection between multiple conditions affects people's experiences, the ways and means of maximising the likelihood that they will be best placed to adapt can – and should – be established as soon as a person is diagnosed with a single condition – and indeed ideally in healthy people too. Habits, attitudes and coping strategies developed before a person has multiple conditions may make all the difference.

For each principle below, questions are posed to suggest possible interventions or improvements.

1. Promote mobility

Once mobility is compromised or lost it can be very difficult to recover it, with consequences for physical health and mental wellbeing. A loss of mobility, often linked to increased pain, can mean the end of work, the curtailment of many social interactions and reduced independence. Those who manage to maintain mobility are often those who seem best placed to cope with and adapt to life with multiple conditions.

For policy/service design: How can maintaining and improving mobility be embedded as a priority for all health and social care services? How can physical activity be promoted for healthy people too so that they are mobile and fit before any diagnosis occurs?

For health and social care professionals: Does the course of action you are recommending explicitly consider any impact on mobility and the barriers the individual is experiencing? When it comes to mobility, might the treatment from one specialist contradict the treatment from another? Are there aids and adaptations available that can support independent living in the home? Can tailored programmes of physical activity be provided, ensuring that they reflect different people's abilities and are adapted when abilities change?

For charities/support groups: What role can you play in helping your audience maintain or improve mobility? Can campaign messaging have a focus on mobility, as something that can affect anyone?

For carers: What support can you give and what support do you need? Are there things you could do together to improve or maintain mobility for both you and the person you care for?

For individuals: Can you link a daily or frequent activity to the goal of maintaining your mobility, e.g. walking the dog?

2. Encourage the person to take an active role in the management of their condition(s)

People who felt in control or who perceived that they had a degree of agency over their conditions or treatment were more likely to develop and adapt coping strategies and feel optimistic about their future. While undeniably necessary or helpful in the short term, many purely medical interventions have the potential to inadvertently reduce agency if not framed in the right way. In addition, people with multiple health conditions that require lots of different interactions or support that takes up a lot of time may begin to feel burdensome.

For policy/service design: Can services be designed so that people are encouraged to take as much ownership of their treatment as they are comfortable with? How can professionals be motivated to consider care beyond the purely medical aspect and prompt shared decision-making? Empowerment means personalisation, rather than a one size fits all approach – can training be provided to support these conversations and make them productive?

For health and social care professionals: Can you give people the time, information and support they need to make decisions in partnership with professionals? Can social prescribing be encouraged, where appropriate, and GPs be provided with community assets maps so that they are aware what is available in their area?

Can care be streamlined and handled by a case manager/navigator who acts as a regular point of contact within a clinical team with access to relevant records, and who supports access to other non-health services?

Could there be more clarity about which aspects of care and treatment the individual is responsible for, and which aspects a health and care professional is responsible for?

For charities/support groups: How can people be encouraged to take an active role in the management of their condition, going beyond the medical aspects to consider wider physical, emotional and practical action? Can a more proactive role be taken in signposting to resources?

For carers: How can carers be empowered and enabled to be supportive ‘partners’ in the management of care, minimising any risk undermining agency?

For individuals: What information, support and feedback would help you feel more in control of your treatment and care?

3. Help the person identify achievable goals

These might be physical, emotional or social, and they might be longer-term ambitions or more ‘bite-sized’ goals to help someone through their day. People that were clear of what they were trying to achieve appeared more likely to maintain a positive attitude and adapt their lives to changed circumstances. Whether this is clinicians asking what other treatment a patient is receiving and how they feel their other conditions are being managed, or building up a picture of mental wellbeing, knowing what else is important to the person allows scope to tailor treatment and advice to fit with their other priorities or challenges. Treating someone holistically does not mean having to provide the whole of their support; simply pointing people in the direction of other services or support gives them broader options. There is also a need for greater information-sharing between clinicians and other care providers to minimise the amount of times somebody has to repeat their story.

For policy/service design: Mental wellbeing is, in many ways, as important as physical health. Can mental wellbeing be embedded as an outcome of all services? Similarly, can techniques widely used to treat mental health conditions, e.g. CBT, be adapted to be part of a holistic care package explicitly aimed at helping people develop coping strategies? Can policy reflect that care should be measured on quality of life outcomes rather than purely on activity?

For health and social care professionals: Try to find out what else is going on in someone else’s life. Is wider mental wellbeing part of the conversation? Encouraging people to talk about how they are feeling, or the things that make them feel better can reveal opportunities to provide additional support. Can effort be made to consolidate tests and appointments into a couple of days so that people have the best chance at staying in employment? Can occupational therapists be engaged more frequently?

For charities/support groups: Is there scope to do more to support people’s experiences of life beyond their treatment, and help them to be ambitious about what is achievable despite their conditions? Could more be done to signpost to other services as part of a holistic experience of care? Can charities do more to increase awareness, normalise experience and offer support?

When people are angry about losing something through poor health, can they be encouraged to find ‘the next best thing’, or to find an alternative? Change the dialogue – just because one goal is lost or out of reach now, does not have to mean no other goal is achievable. Avoid making solutions overly-professional.

For carers: How can you support and encourage people with multiple conditions to set and work towards achievable goals without increasing dependency?

For individuals: How can you break down ambitions into daily or weekly goals that will make you feel better – physically, mentally or emotionally?

Conclusion

A loss of mobility, which often occurs in tandem with pain, may contribute to disconnection from social life, and has a significant impact on a person's ability to deal with multiple health conditions. By its nature, mobility is often ignored until it is a problem – by which time it is more difficult to address. Actively promoting the maintenance of mobility – including among healthy people – could bring great benefits.

Life with multiple health conditions can be frustrating, confusing, and can lead people to feel they are a burden on the system and their loved ones. This can be offset when people feel empowered in their own health care, and their wider life, whether this means them being better supported to navigate the system, feeling able to ask questions and knowing who to ask, or having shared conversations with health and care professionals.

Making goals, feeling purposeful and having routines can all affect somebody's mental wellbeing. Living with multiple health conditions can make these things harder. Taking an approach that goes beyond the clinical setting, could help people realise that when old goals are lost, new goals can still be made.

These principles can help establish the holistic approach needed to create the conditions for people with multiple conditions to live the lives of their choosing.





The Taskforce is uniquely positioned to work across boundaries. Combining the voice of 14 leading health and care charities within the Richmond Group of Charities, the place-based insights from Guy's and St Thomas' Charity and views of primary care professionals from the Royal College of General Practitioners. We are proud to partner together in increasing understanding about the importance of this issue.

Part two

Taskforce Response



About the Taskforce on Multiple Conditions

Building on the considerable body of literature and initiatives in this field, we aim to bring a collective focus to, and start to deliver collaborative action on, multimorbidity. The Taskforce recognises the substantial breadth of this agenda and the need to apply focus to a small number of priority areas.

Specifically, we will do this by exploring the current and potential voluntary and charity sector contribution to improving outcomes and influencing service redesign in partnership with others in collaboration with all parts of the health and care system.

The Taskforce is uniquely positioned to work across boundaries. Combining the voice of 14 leading health and care charities (some of whom are set up to focus on single conditions but recognise the people they support will often be managing other conditions alongside) within the Richmond Group of Charities, the place-based insights from Guy's and St Thomas' Charity and views of primary care professionals from the Royal College of General Practitioners. By pooling our insight, policy and practice, the Taskforce can demonstrate more clearly to system leaders what works and what doesn't with a more coordinated voice than members acting alone. We are proud to partner together in increasing understanding about the importance of this issue.

The Richmond Group of Charities knows from our earlier report on 'Multimorbidity: Understanding the Challenge' as well as our day to day connections with people referring into our services, that we need to work collectively if we are to best care for people with multiple long term conditions.

Guy's and St Thomas' Charity works in partnership with many to help tackle big health challenges that affect inner-city areas, including multiple long-term conditions. Through its place-based work, including its recent research, 'From one to many – Exploring people's progression to multiple long-term conditions in an urban environment', the Charity is exploring what impacts on the development of multiple conditions and sharing lessons with others.

The Royal College of General Practitioners recognises that GPs are central to providing excellence in primary healthcare for people living with multiple, long-term conditions; but to effectively address the complexities of care for these people, a multi-disciplinary approach is required, where partnership with the voluntary sector is imperative.



To bring a collective focus to, and start to deliver collaborative action on, care for people with multiple conditions.

What does this research tell us about how people experience living with multiple long term conditions?

The ethnographic research shows a clear and overarching theme of how those living with multiple conditions experience a series of losses as they develop multiple conditions. These losses can vary from the practical to the highly personal, and while experiences differ between individuals, some clear patterns emerge. As impact accumulates over time, we see a progression of losses that take in loss of independence, loss of professional identity, loss of earnings, loss of security, loss of relationships and in the widest sense loss of a person's former 'healthy self'. As Anna puts it; *"It's frustrating that no matter how self-controlled I am, my resistance to insulin will grow and there's nothing I can do to stop that."* Across the stories of our 10 participants, there were three areas of loss which stood out:

Too often in this report we hear of the impacts of **(1) loss of mobility**, which contributes to **(2) diminished social connections**, loneliness and varying degrees of **social isolation** which in turn can contribute to **(3) a loss of mental wellbeing**. These were repeated themes that are evidently interdependent and can be mutually and negatively reinforcing. Often, there are very practical barriers (for example, lack of transport or suitable mobility aids) that can contribute. Another common barrier to wellbeing, and a factor in reduced mobility and social connection, is the impact of chronic pain.

Chronic pain underpins the daily routines of many of our participants, often significantly depleting peoples' energy reserves and emotional resilience (described in the report as health 'bandwidth').

A paradox is at play; as the diagnoses mount up, they can become less visible or significant as individual conditions. When our participants describe their experience of MLTCs it is often not in condition-specific terms. As Susan puts it; *"It's all just one big chunk of pain."* This daily debilitating impact of pain was an overriding factor for many of our participants and it seems clear that pain management strategies should be an imperative part of an individual's care and support plan, addressing the complexity and cross-cutting needs of the whole person.

Beyond physical health, we also see a range of unmet needs, both psychological and practical, as people with multiple conditions attempt to manage their cumulative impact. Multiple conditions mean multiple appointments which can be costly, time-consuming and difficult to manage around work commitments. For those unable to work, the financial impacts are acute and welfare assessments, benefits payments and housing insecurity are common worries. Some participants are no longer able to work and feel their life has lost a sense of purpose. All the above are contributing factors to loss of agency. For Paul, he misses his job more than anything else: *"I felt worthy, I felt like I was doing something and that is what I miss."* A fragmented health and care system geared towards single conditions places extra burden on people managing multiple conditions, their needs – whether physical, emotional, practical or other – need to be understood holistically.

We need to think about mental health diagnoses in their individual sense, but also consider the impact of MLTCs on people's mental health. A lack of more general awareness and understanding as to the barriers those with MLTC face can leave people unsupported. The psychological impact of living with multiple conditions can involve negative thoughts (of hopelessness, fear of the future), negative feelings (sadness, anxiety, irritability) and behaviours (such as avoiding meeting friends and relatives or difficulties in taking medications). For example, as Wendy describes: *"I'm comfortable with schizoaffective being a part of me. But the physical pain, it affected my personality."* All people need support to build both physical and emotional resilience.



The ethnographic research shows a clear and overarching theme of how **those living with multiple conditions experience a series of losses.**

It is never too early to consider emotional wellbeing issues for those who don't disclose or have a diagnosable mental health condition. We also see the importance of reassessment as circumstances or needs change. Routine monitoring would be a simple but powerful secondary prevention tool. And for those with more severe mental health diagnoses, evidence shows that physical health needs are at risk of neglect. There is work ongoing to look at this particular issue and how physical health needs can be equally well supported in this group¹⁰. But we need to think about the less severe end of this continuum too.

If loss is a central theme, so too is adaptation. We see people employing a range of inventive coping strategies and adjustments to better manage their conditions and to live as well as possible. And what helps isn't always medical. Godfrey, for example, takes great comfort and joy in his beloved Jack Russell 'Muppet'. In fact, 9 out of our 10 participants had a pet, and while the sample size is small, this seems a striking fact and suggests the power and value of looking after and having the company and comfort of an animal. For Matilda and Peter, they describe how the routine and responsibility for feeding and caring for their pets provides a reason to keep active day to day.

Others have developed self-described 'tricks' and 'hacks' as to 'what works', tailoring resources to better suit their individual circumstances. Wendy has devised a 'bliss list' of things that make her happy, adapting a sophisticated spreadsheet to keep track of her symptoms. Susan's husband has made several DIY home adaptations, attaching wheels to all the furniture and an extender plug socket to the wall, carefully observing Susan's day to day activities to 'find a problem and think of a solution'. These adaptations show the resilience and determination of people as they look to mitigate the impact of their multiple conditions and retain or gain back independence.

For some, we see the value of meaningful relationships and a 'new' routine to adjust to a new way of living. For Megan; "...volunteering at the cafés and art Mondays, and then my therapist on Wednesdays means I have a bit more structure." Family, friends and neighbours can offer a vital support network, relied upon for both practical assistance and emotional support, though many participants also share a common fear of 'becoming a burden' to those around them. Participants describe the value and joy they take from a variety of activities. Examples range from paid work to volunteering, spending time with family and pets, painting, listening to music, spending time in nature, and other kinds of social connections. We see then how people's wellbeing is rooted in their wider social circumstances – work, housing, relationships, community, environment and play.

Another strong theme was the nature of the relationship between those managing multiple long-term conditions and their healthcare professionals. There were very positive examples described as well as examples of over-dependence or absence of engagement and distrust. What was widely acknowledged was the value placed on continuity of care with a trusted professional, particularly with a person's GP. Keith has developed a very positive relationship with his GP and will "...store up several small health issues and compile a list" spending a few minutes at the end of his appointment catching up about favourite music and new albums by bands they each follow. Conversely, Vivienne finds her masseuse can be of more help than a GP; "after one appointment with my masseuse the pain just lifted. If I had more money I'd go and see her all the time." The nature of the skill mix and variety of professionals in primary and community care is already being explored, and this research suggests that people with multiple conditions should be centrally considered in that work.

These case studies often reveal the same issues, but with different outcomes. What do we need to understand more? How and why do people's experiences differ?

This work builds on the Richmond Group of Charities report earlier this year 'Multimorbidity: Understanding the challenge'¹¹ which identified considerable gaps in knowledge on this topic. We know that multimorbidity occurs 10–15 years earlier in people living in the most deprived areas than it does for those living in the most affluent¹².

And as Guy's and St Thomas' Charity recent report, 'From one to many: Exploring people's progression to multiple long-term conditions in an urban environment'¹³, demonstrates, this is not just a problem of old age. It seems clear that we need a public health approach to this issue that takes account of socioeconomic inequality and deprivation. We need to understand more about where the 'journey' from single to multiple conditions begins, the role of risk factors and the wider social context and impacts of inequity. It is critical we connect together these issues, invest in early prevention strategies where disease trajectories can be slowed down or prevented and gain a deeper understanding of the social determinants of health and health behaviours.

It is also worth reflecting on what is left unsaid. We see a series of missed opportunities – critical moments that might have changed a person's trajectory, but hard to identify 'in the moment'. Whilst some participants made connections with local voluntary and community sector support, the majority of participants didn't talk about (and perhaps hadn't thought about) social care or support from charities or other voluntary organisations at all, and so had no real engagement or support this way. This is an important finding in itself. Many of the unmet needs identified are for just this type of non-clinical support (e.g. help with transportation, welfare needs, encouragement to take up a new hobby or move more, social networks and communities to connect and engage with). We need to understand how to ensure that people are clear about what they can ask and expect of the health and social care system.

As well as measuring how supported people feel to live with their conditions and whether they are able to meet the goals and priorities in their own lives, this ethnographic research clearly shows that peoples experience of using services (especially when its multiple services) and the impact that has on them is

often a very significant part of their story. A disjointed health and care system means that issues can be compounded for those managing multiple conditions.

For example, one person sharing her story of managing multiple conditions talked about attending 65 medical appointments over the course of one year. Similarly, Nichola, an Expert by Experience advising the Taskforce manages over 10 conditions, attends four hospitals, has six consultants, two physiotherapists and one speech and language therapist.

We want to understand what opportunities there are for more coordinated support and streamlined care – and to better equip health and social care professionals to understand the practical and emotional implications of managing multiple conditions. Can we alleviate some of this administrative burden and identify the most 'reachable' moments to offer support?

Another clear message from people managing multiple conditions is that the term 'multimorbidity' is not one that they understand, like or would use themselves. In fact, there was a strong reaction against the term. For Vivienne, "*it's a horrible word, it just sounds like death.*" For Matilda, "*it sounds like you are about to die.*" There is no common narrative around the experience of managing and living with multiple conditions. Phrases like "*you name it, I've got it*" and "*It's just one thing after another*" were used by study participants. The Taskforce wants to better understand how to frame, describe and talk about multiple conditions, to help people living with them but also to enable those helping and supporting them to recognise and communicate, identify and understand.



We need to understand more about where the ‘journey’ from single to multiple conditions begins, the role of risk factors and the wider social context and impacts of inequity.

Important areas not addressed by this research

Clearly, there are limitations to what we can assert based on a sample size of ten people, who are for the most part, young or middle-aged.

This research deliberately chose to focus on the <65 demographic as we know that managing MLTCs is not only a problem of older age. However, given that the scale of this ethnographic research was small, there may be value in the future of conducting further quantitative research to test some of the findings and themes and to understand the patterns and trueness across different demographics – be it age, ethnicity, geography, gender, deprivation etc. Although outside the scope of this particular study, it is not outside the scope of the focus of the Taskforce; when we come to look at solutions, attention also needs to be given to social care and in particular, support for carers (many of whom are themselves living with MLTCs). Many people with multiple long-term conditions also rely on social care support and the 2011 Census found that there are an estimated 6.5 million people in the UK providing unpaid care for adults in the UK of whom an estimated 1.5 million are over 65¹⁴.

There is also the issue of frailty and how we can best care for vulnerable and/or cognitively impaired adults – generally older than those described in the research – many of whom will not have the means to be dealing with some of the solutions discussed here. Another key issue is end of life care and care planning towards the end of life. We know from the literature that most hospital inpatients have multiple conditions and a high proportion are in the last year of life. These are all an important part of this debate and will need to be part of the solutions conversation.

Given that the scale of this ethnographic research was small, there may be value in the future of conducting further quantitative research to test some of the findings and themes and to understand the patterns and trueness across different demographics.



6 million unpaid carers for adults in the UK of whom an estimated 1.5 million are over 65.

How we can respond to the challenges identified? Some thoughts on solutions:

The Taskforce has set out 4 key priority areas for activity in Year 1, which are:

- P1** **Priority 1:** Better Understanding of Lived Experience
- P2** **Priority 2:** Co-ordinating information & support offers of The Richmond Group of Charities and beyond
- P3** **Priority 3:** Building our insight on health and deprivation
- P4** **Priority 4:** Prevention

We understand that it is not possible to make detailed policy recommendations on the back of this single ethnographic study. However, this work builds on the wider evidence gathered from the Taskforce and our separate member organisations in recent years. Consolidating that learning, we have mapped out the following key areas for more detailed investigation within our priority framework. Given the breadth of these items, we will not be able to take forward all of these at once, but will be using these areas to prioritise our next steps as a Taskforce.

Table 1: Delivering person centered care for people with MLTCs – potential areas of focus for the Taskforce

| | | |
|---------------------|---|--|
| <p>P1</p> <p>P2</p> | <p>Holistic needs assessments and care planning</p> | <p>Care planning should be anticipatory (forward looking), and take account of people as a whole i.e. a 360 degree review. Plans should be collaborative between the individual and HCP (perhaps with other professional or family members present) and include consideration of the domains of pain and functional limitations, and a person's confidence, capability and knowledge to manage their health. Such conversations are an opportunity to clarify goals, options, preferences and crisis planning all based on this mutual understanding. Care planning is rooted in the principles of shared decision making and co-created solutions that are based on the input and challenge of people using health and care services and their families.</p> |
| <p>P1</p> <p>P2</p> | <p>Social prescribing</p> | <p>'Social prescribing', as described by the NHS and others, links people with health problems into practical and emotional support in communities and the voluntary sector, often via their GP. Overall it seeks to address people's needs in a holistic way and support them to take greater control of their own health and wellbeing. This can be done in different ways, but many approaches involve link workers or 'connectors' (who work with people to identify which practical, emotional and community support can best help them achieve their goals) as well as 'builders' (who work within communities to ensure relevant support is available locally to meet people's needs). We have learned from our 'Doing the Right Thing' work in Somerset that there is no definitive model of developing and implementing social prescribing – each area has different assets, infrastructure and relationships upon which to build. However, because social prescribing seeks to interface the statutory sector and VCS, we've found that successful and sustainable approaches are based on collaboration within and across these sectors. This includes recognising and funding the crucial role of the 'builders', as well as transferring resources from the statutory sector to the VCS (in parallel with the connections being made across the sectors).</p> |
| <p>P2</p> | <p>Care coordination roles</p> | <p>Invest in and make coordination a clinical responsibility. Evidence shows goal-setting conversations can be effectively led by non-medical staff and the voluntary sector, an approach which can allow more time and space for discussion and to identify appropriate support (and to identify informal carers and take action on their support needs too). This requires moving towards team based care. Care coordinators could reduce pressure on healthcare professionals, whether filled by the GP practice or via local voluntary groups.</p> |
| <p>P2</p> | <p>Support for General Practice and Community Nursing</p> | <p>Primary care has a major role in diagnosing, treating and supporting patients who are living with multiple conditions. If healthcare professionals are expected to lead meaningful and potentially difficult goal-setting conversations alongside their already heavy workload, they must be allowed the space and time to do so. We need to take care of those leading our services – and look after their own health and care needs.</p> |
| <p>P1</p> | <p>Use patient reported outcome measures of wellbeing</p> | <p>Measure and consider incentivising outcomes and experiences that matter for people with multiple long-term conditions. This will likely need to focus on the impacts of conditions rather than only clinical activities or biomarkers – such as pain, fatigue, mobility, breathlessness, to look at issues such as work, housing or loneliness along with experience of using services themselves.</p> |
| <p>P1</p> | <p>Parity of esteem between physical and mental health</p> | <p>Equal recognition of the importance of mental health alongside physical (and the inverse). The interface between physical and mental ill health needs to become a normal and central part of all clinical practice. How can we identify problems earlier and delay their progression? This requires proactive working and capacity within existing workloads and valued as central to good service (and therefore recognised in service specifications).</p> |
| <p>P2</p> | <p>Implement wider training and education for healthcare professionals</p> | <p>Healthcare professionals should be properly supported in their understanding of collaborative care planning. Medical and nursing education needs to change – we need specialists, but we also need people who understand interdependencies and managing multiple long term physical and mental health conditions.</p> |

| | | |
|----------|---|---|
| P1 | Encourage patient activation and self-care | Can services be designed so that people are encouraged to take as much shared ownership of their treatment as they are comfortable with? Can effort be made to consolidate tests and appointments so that people have the best chance of staying in employment? For example, can Occupational Therapists be engaged more frequently? |
| P4 | Promoting movement and mobility | Building on our partner programme 'Movement for All', how can movement be promoted and encouraged for people at risk of developing LTCs, so that they are mobile and fit before any diagnoses occurs? How can movement help prevent or delay the progression from one to multiple LTCs? Can we build better support systems that enable and support people to be active? Linked to this how can mobility be prioritised to help people retain independence and halt progression of illness? |
| P2 | Polypharmacy and de-prescribing | Medicines management becomes more of a challenge in this group as the effects of drugs and their side effects are more complex. An ongoing review process is crucial to recognise changing needs, developing side effects and adverse events, particularly when someone moves from one care setting to another. How can we support pharmacists, who are often very well cited on this group of people, and who are an untapped asset in the care of people with MLTCs? |
| P2 | NICE guidance to recognise clusters of comorbidities | Including those which are especially debilitating. Can we shift the narrative to focus on cross-cutting psycho-social impacts on the individual? As a minimum, an annual review of any one condition must take account of the fact the person is normally managing more than one. |
| P3 | Build the evidence base | Older people and multi-disease have often been systematically excluded from studies. Research groups, grant-giving bodies and journals are looking to address the evidence gaps. We can work as a collective to support the organising frameworks to help researchers and funders commission research on outcomes that are patient-led. |
| P1 P4 | System planners and commissioners | We need strategies to address variation of need in local populations as well as workforce and pathway redesign. Local data and agreed approaches should be captured in Joint Strategic Needs Assessments and Joint Health and Wellbeing strategies to support commissioning of services and GP practice accountability. |
| P1 | Data sharing | None of this will work if we don't get data to flow within and between different parts of the health and care system (with appropriate consent). We also need an interoperable shared care record the whole team sees and can work with, including the patient and their carer(s). |

Building on these findings, we have identified the following practical set of activities for the Taskforce to take forward initially, working with our Expert Advisory Group, to:

- **Look at our own national information and support offer:** We say plan to explore how The Richmond Group of Charities can challenge its own information and advice offer to respond to people managing multiple as well as single long-term conditions. How best can we use our voice to mobilise and effect policy in a way that addresses the social context in which people live? As a first step, we are embarking on an inward look at the support offer across our 14 national charities for opportunities to align, where there is merit in doing so. We plan to: Identify existing assets and develop a shared understanding of our national ‘remote’ offer of information and advice (e.g. digital resources, helplines); agree ambitions and outcomes that matter to people and are helpful to the system; and, explore opportunity for how this might interact externally with public health, primary, community, acute and social care settings.
- **Move towards solutions in collaboration with people with multiple long-term conditions:** We must do more than just draw attention to what people’s lived experiences with health and social care services look like. The Taskforce will work to ensure more people living with multiple conditions and their carers are engaged in the debate about addressing care needs and what comes next. In the next phase of our work programme, the Taskforce is committed to securing the views of people with MLTCs, carers and family members for what needs to change. We will also engage with a wide range of health and social care professionals, starting with primary care, asking their views as to what creates the barriers to change. We recognise GPs cannot address the complexities of care for this group alone and will be extending our reach across the system (specialists, pharmacists, link workers, social workers, local authorities etc).
- **Support the research agenda:** Build the evidence base and generate deep knowledge about MLTCs to ensure we have the insights needed to underpin policy and strategy. We seek to stimulate further research into the impact of living with multiple conditions, with an emphasis on exploring and gaining a greater understanding of people’s lived experiences, including those of families and carers. This work will begin with a research seminar, to present these findings and work with key research groups to help shape future research priorities.
- **Re-frame language:** Existing language is not person friendly (particularly the term ‘multimorbidity’). Our Taskforce partners Guy’s and St Thomas’ Charity are conducting a research evaluation to deepen our understanding of how MLTCs can be better communicated across the wider system. We want to change the language and widen the biomedical lens to engage more people living with MLTCs in this debate. We will work with them to share insights widely.

We hope that by sharing this research giving voice to the lived experience, we can encourage cultural and behavioural change across the health and care system and secure a better deal for all people living with multiple long-term conditions.



**If we want to encourage people to be independent,
they need to be able to depend on the system.**

Appendix 1: Participant conditions

| Condition | Number of participants with this condition | Condition | Number of participants with this condition |
|-----------------------|--|------------------------------|--|
| Anxiety | 1 | HIV | 2 |
| Asthma | 2 | HIV related memory loss | 1 |
| Atrophic pancreas | 1 | Hypertension | 4 |
| Avascular necrosis | 1 | Hypothyroidism | 2 |
| Bipolar disorder | 1 | IBS | 1 |
| Bulimia | 1 | Insomnia | 1 |
| CHD | 1 | Ischemic heart disease | 1 |
| COPD | 1 | Musculoskeletal Disorder | 1 |
| Depression | 3 | Osteoarthritis | 1 |
| Diabetes (Type 1 & 2) | 5 | Peripheral Neuropathy | 1 |
| Diverticulosis | 1 | Prostate cancer (metastatic) | 1 |
| Enlarged prostate | 1 | Psoriasis | 1 |
| Epilepsy | 1 | Psychosis | 1 |
| Fused spine discs | 1 | Reflux | 1 |
| Hashimoto's Disease | 1 | Respiratory problems | 1 |
| Heart attack | 1 | Schizoaffective Disorder | 1 |
| Heart murmur | 2 | Sciatica | 2 |
| Hiatus hernia | 1 | Stroke | 1 |
| High cholesterol | 2 | | |

Appendix 2: Full methodology

The research team conducted three-four-hour depth interviews with ten participants living with multiple long-term health conditions. Fieldwork was conducted in Spring 2018.

Desk Research and Knowledge Download Workshop

Prior to fieldwork desk research enabled the research team to develop a clearer understanding of what is already known and discussed about life with multiple long-term conditions. This also helped to inform our sampling considerations and the structure of the discussion guides. The sources were processed with the below questions in mind and then discussed, questioned and added to at a knowledge download workshop in February with Revealing Reality and the Richmond Group Taskforce.

- What data / statistics are there about life with multiple conditions?
 - What can be learned from this data?
 - What conditions commonly come together?
 - How prevalent are different things?
- What are the biggest challenges for those living with multiple conditions?
 - What conditions tend to clash with each other?
 - What impact does it have on mental health?
- How do people with multi-morbidity manage their different conditions?
 - What is the support & treatment like for people with multiple health conditions?
 - What services are there that specifically talk about multiple conditions/‘holistic care’?
- What are the challenges within the NHS of delivering services for people with multiple health conditions?
 - What innovation has there been in living with multiple health conditions?

Key sources

Aiden, H. *Multimorbidity: Understanding the challenge*, January 2018.

Barnett, K, Mercer, S, Norbury M, Watt, G, Wyke, S & Guthrie, B. ‘Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study’, *The Lancet*, Volume 380, Issue 9836, 2012, Pages 37-43.

Bramley, D & Moody, D. *Multimorbidity – the biggest clinical challenge facing the NHS?* November 2016.

Goodwin, N, Curry, N, Naylor, C, Ross, S, Duldig, W. *Managing people with long-term conditions*. The King’s Fund, 2010.

Guy’s and St Thomas’ Charity *From one to many: Exploring people’s progression to multiple long-term conditions in an urban environment*, July 2018.

Hall, P & Holder, H. *Real Lives: Listening to the voices of people who use social care*, September 2016.

Melchiorre, M *et al.* ‘eHealth in integrated care programs for people with multimorbidity in Europe: Insights from the ICARE4EU project’, *Health Policy*, Volume 122 , Issue 1 , Pages 53 – 63.

Melzer, D *et al.*, *The Age UK Almanac of disease profiles in later life*, 2015.

Sample breakdown

Chronic illnesses: respondents suffering with two or more chronic illnesses (please see Appendix 1 for a full breakdown of illnesses covered in this research)

- Gender: 40:60 split (male: female).
 - Age: between 24 and 81, including:
 - One respondent aged between 18-30
 - Three respondents aged between 31-49
 - Four respondents in 50s
 - One respondent in 70s
 - One respondent 80+
- SEG: elicited from living situation, household income, occupation, previous income and occupation if retired or stopped working. Included seven respondents from C2DE backgrounds.
- Housing type: included three living in social housing and two in inappropriate housing.
- Location: four respondents in Southwark and Lambeth, two respondents in Somerset and four remaining respondents offering an equal spread across England.
- Rural v Urban: respondents' locations ranged from extremely rural to suburban and urban settings.
- Life stages: including:
 - Working age – no dependents.
 - Working age – dependents.
 - Older more active – couple.
 - Older more active – lives alone.
- Ethnicity: included 3 x BME respondents.
- Location: included a mixture of those living in rural, urban and suburban areas:
 - Three respondents living in Southwark & Lambeth.
 - Two respondents living in Somerset.
 - One respondent living in Cambridgeshire.
 - One respondent living in Northumberland.
 - One respondent living in the Wirral.
 - One respondent living in the Peak District.
 - One respondent living in Leeds.



Other quotas:

- Minimum 1 x respondent who has recently become multimorbid (within the last 1-2 years).
- Minimum 1 x respondent who lives with a partner who is also multimorbid.
- Minimum 2 x respondents who have both mental and physical chronic illnesses.
- Respondents receiving a range of different health care, including acute, primary, and outpatient clinics.
- Respondents with a range of support networks from well supported to poorly supported.
- Respondents to not all have the same risk factors e.g. smoking and obesity.

Interview approach

The depth interviews used a semi-structured discussion guide – the key sections of which are outlined below – but were designed to be open-ended and relatively informal to allow unexpected insights as well as potentially sensitive issues to arise spontaneously. The interviews were carried out face-to-face in respondent's homes, with a view to establishing a relaxed atmosphere and gaining respondents' trust.

Areas of questioning

- Introduction: living situation; housing; area; family.
- Day to day life:
 - How would they describe their quality of life?
 - What do they do on a daily basis?
 - How independent do they feel in the home?
 - What problems do they experience with their mobility and/or dexterity?
 - What is important to them?

Data capture tools: Wheel of life & Weekly routines timetable

- Identity:
 - How do they see themselves?
 - What roles do they have? What “hats” do they wear?
 - How do they present themselves to different professionals?

Data capture tools: Identity mapping & How am I ‘seen’ by different people

- Wellbeing today:
 - What hinders them on a daily basis?
 - How do their symptoms fluctuate over time?
 - How do they manage their symptoms?
 - What approaches have they developed to symptom management?
 - How do they prioritise different symptoms?

Data capture tools: Symptom map

- Condition timelines:
 - Diagnoses dates?
 - Treatment periods?
 - Key events and impacts?

Data capture tools: Conditions timelines

- Social networks & support:
 - What is their social network like?
 - Who can they depend on for support?

Data capture tools: Social network map

- Support services:
 - What interactions do they have with health and social care professionals?
 - Do they have any preferences for certain professionals? Why?
 - How they decide where to go for help?
 - What are the missed opportunities for professionals?

Data capture tools: Interactions table

- Reflections and future:
 - What are their goals for the future?
 - What do they worry about in the future?
 - How would they describe life with multiple long-term conditions?
 - What language do they use around their health?

References

Part one

1. Chronic pain is defined by NICE as “pain that persists or recurs for longer than 3 months’. Examples of specific conditions that can induce chronic pain include low back pain and sciatica, rheumatoid arthritis and osteoarthritis. www.nice.org.uk/guidance/indevelopment/gid-ng10069/documents
2. Aiden, Hardeep, *Multimorbidity: Understanding the Challenge*. A report for the Richmond Group of Charities, January 2018.
3. David Melzer *et al*, *The Age UK Almanac of disease profiles in later life*, 2015.
4. The Taskforce on Multiple Conditions is made up of the Richmond Group of Charities, Guy’s and St Thomas’ Charity and the Royal College of General Practitioners.
5. Aiden, Hardeep *Multimorbidity: Understanding the Challenge*. A report for the Richmond Group of Charities, January 2018.
6. Navickas, Rokas *et al*, Multimorbidity: What Do We Know? What Should We Do? *Journal of Comorbidity* 6.1 (2016): 4–11. PMC. Web. 18 June 2018.
7. *Ibid*.
8. Names have been changed to protect the privacy of individuals.
9. Such as Access to Work, which seeks to provide much needed support to people with disabilities and long-term conditions in the workplace.

Part two

10. See the Equally Well initiative: www.equallywell.co.uk/about-us
11. *Multimorbidity; Understanding the challenge*, A report for the Richmond Group of Charities, Hardeep Aiden, January 2018.
12. Epidemiology of multimorbidity and implications for health care, research and medical education: a cross-sectional study Karen Barnett, PhD, Prof Stewart W Mercer, PhD, Michael Norbury, MBC, Prof Graham Watt, MDProf Sally Wyke, PhD, Prof Bruce Guthrie PHD Open AccessPublished:May 10, 2012DOI: [https://doi.org/10.1016/S0140-6736\(12\)60240-2](https://doi.org/10.1016/S0140-6736(12)60240-2)
13. *From one to many: Exploring people’s progression to multiple long-term conditions in an urban environment*, Report by Guy’s and St Thomas’ Charity and Kings College London, 2018.
14. House of Commons BRIEFING PAPER Number 7756, 22 November 2017

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“Just one thing after another”

Living with multiple conditions

A report from the Taskforce
on Multiple Conditions

October 2018

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The
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