

Facing the future

Ageing with type 1 diabetes and the need for change June 2025

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Contents

Our supporters

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Foreword

Karen Addington, Breakthrough T1D Chief Executive

For the first time, a generation of people with type 1 diabetes (T1D) are living longer than ever before. While this is a milestone worth celebrating, there is limited research, policy and clinical focus to identify and address the needs of people who are ageing with T1D.



Getting older with T1D presents unique and complex challenges. As the body ages, physical limitations, cognitive decline and dealing with multiple health conditions become more common.

These make the daily demands of living with type 1 diabetes even more difficult. For women, hormonal changes during the menopause can have a huge impact on their physical and emotional health, and crucially, on their ability to manage their diabetes.

The voices, concerns and needs of older people with T1D are currently not being recognised and acted on. This must change if we're to make sure that older people have access to the treatment, care and support that is essential to living well with T1D at every stage of life.

As life expectancy for people with T1D rises, the health and care sector must adapt. Treatment, care and decision-making must be shaped in genuine partnership with people living with or caring for someone with T1D.

At Breakthrough T1D, we set out to develop real-world insight in this under-researched area. Grounded in the real, lived experience of people aged over 45 with T1D, we commissioned this market research to identify the barriers they face and their fears for the future. What we found was deeply concerning.

People described ageing with T1D as a battle – one that brings increasing anxiety and challenges. While diagnosis is widely recognised as a major life adjustment, many felt that managing the condition in later life was an even greater struggle.

They spoke of having to fight for essential treatment and support, whether that was accessing medication to manage menopausal symptoms or receiving appropriate care in hospital.

There were also serious concerns about the level of training or understanding to manage a condition as complex as T1D.

For women with T1D, menopause can be particularly challenging without support or specialised care. Some women told us how the absence of proper guidance and medical support left them feeling overwhelmed, anxious and at a loss for how to cope.

The stories shared in this report are a powerful testament to the additional struggles faced by people ageing with T1D. Based on personal experiences, people told us about hospital stays where their insulin was locked away, dosages were denied, or they had to self-advocate for their own care.

We have an opportunity to shift models of T1D health and social care: to optimise people's health and quality of life in older age by working in genuine partnership with those living with T1D.

By recognising their expertise through lived experience and designing training, treatment, and care around their needs, we can change the future of T1D in older age.

This report reveals that ageing with type 1 is a ticking time bomb. Without urgent action, an entire generation faces unnecessary hardship, preventable complications and a health and care system unprepared to meet their needs.



About T1D and ageing

T1D is a serious autoimmune condition. It affects both children and adults, regardless of their diet or lifestyle. Over 400,000 people in the UK are living with T1D. There is currently no way to prevent it, it can be fatal and at present, there is no cure.

With T1D, the pancreas stops producing insulin, the hormone the body needs to get energy from food.

This means a process the body should do naturally and automatically becomes something a person with T1D must look after themselves every day. Without insulin, a person with type 1 would die within a few short days.

People with T1D must constantly monitor blood glucose levels and self-dose themselves with insulin. If blood glucose levels are too high or low and left untreated, it can be fatal or lead to longterm complications such as sight loss, kidney failure, and in some instances, limb amputation.

To treat T1D, people must inject or deliver insulin through a pump, carefully balancing these insulin doses with eating and activity throughout the day and night.

Technology can make everyday life with T1D much easier, supporting people to keep their glucose levels in their target range and avoiding complications.

There is limited research into T1D and ageing, despite 48% of people with type 1 in the UK being over the age of 50¹. The natural ageing process brings changes that can make the day-to-day management more complex and increases the risk of complications.

Physical changes, like reduced dexterity, mobility issues and visual impairment, can make it harder to administer insulin, use diabetes technology or accurately monitor blood glucose levels. Alongside physical decline, studies show that older people with type 1 have a higher risk of cognitive impairment than those without the condition.²

Memory loss, confusion and slower processing can make it more difficult to follow treatment plans, respond to glucose fluctuations and make informed decisions about care. Research has also found a link between long-term glycaemic control and cognitive health, with HbA1c (average blood alucose) levels of 8 - 8.9% or higher associated with an increased risk of dementia.³

Managing multiple conditions is also a significant challenge. Many older adults with type 1 take medications for other conditions, leading to complex treatment regimens. This "polypharmacy" increases the risk of drug interactions, side effects and difficulties adhering to diabetes treatment plans.

For women, menopause presents an additional layer of complexity. Hormonal fluctuations during this stage can significantly affect blood glucose control, making it harder to maintain stability.



National Diabetes Audit, 2020-21, Type 1 Diabetes - NHS Digital
Comparison of cognitive function in older adults with type 1 diabetes, type 2 diabetes, and no diabetes: results from the Study of Longevity in Diabetes (SOLID) - BMJ Open Diabetes Research & Care
Long-term Glycemic Control and Dementia Risk in Type 1 Diabetes – American Diabetes Association, Diabetes Care, PMC

Introduction

This report explores the experiences, concerns and needs of people over the age of 45 living with T1D. We set out to understand what life is like for this group, how they manage their condition and what hopes and fears they have for the future as they get older.

The people involved in our research were diagnosed with type 1 at varying stages of life. Some were diagnosed in childhood, others in adulthood and some much later in life.

Through qualitative and quantitative market research with people with type 1 and those caring for older parents with the condition, we set out the following objectives:

- Understand the experiences and concerns of people with type 1 over the age of 45 and how they felt about ageing with the condition:
- To provide an evidence base to engage and influence the NHS and other services for older people with type 1
- Explore current access and attitudes towards T1D technology and treatments
- To identify the information and resource needs of people over the age of 45 with type 1

Despite the different journeys of people involved in our market research, common themes emerged around the challenges they face and the support they need. Many expressed a deep sense of resilience in managing their condition, yet they also spoke of fears and uncertainty about what lies ahead. People shared with us distressing first-hand experiences in hospitals and care settings, highlighting where vital care was missing. This report sets out our findings and recommendations on the action that is needed to improve the lives of over-45s with T1D, and how to give them greater confidence about their future as they get older.



"I think I'm more optimistic than when I was first diagnosed. I thought I wouldn't live past 30, or I would be blind, missing limbs or have severe complications. I think technology has enabled me to look after myself."



Methodology

This report summarises quantitative and qualitative market research we carried out to explore the experiences of people over the age of 45 living with type 1 diabetes and those caring for family members in this age group.

Quantitative research

A total of 364 people took part in our online survey in October 2024. This included 16 responses from people caring for someone over the age of 45. Of the survey participants, 221 had been diagnosed before the age of 30 and 143 were diagnosed after the age of 30. The survey focused on understanding people's experiences, with more in-depth insight gathered through qualitative interviews.

Qualitative research

The second stage of the market research involved 24 people aged between 47 and 71 who completed a series of tasks through a guided group discovery platform as an online community.

These included mapping their support networks, writing journal-style responses and ranking and sorting lists to determine priorities and the impacts of ageing with T1D. Open discussions also took place with moderators exploring the reasoning behind some of the survey responses.

In November 2024, we held seven focus groups. Two of these took place in person, in London and Stockport, and five were held remotely. The in-person groups were recruited by an external agency with people who hadn't taken part in the earlier stages of the research.

Four of the online groups consisted of participants from the online community, grouped by shared characteristics or experiences to allow more focused discussion. The final online group was made up of people caring for parents with a diagnosis of T1D.

Findings

Our market research shines a spotlight on the challenges older adults living with T1D face in managing their condition as they age, and the gaps in care, support, and information they have experienced.

Life journey

In our market research, participants shared their reflections on ageing with T1D. This included physical health concerns and the oftenoverlooked mental and emotional toll of managing a lifelong condition.

These stories reveal a group of people who have adapted to new technologies and treatments as time has gone on, but who face significant uncertainty and apprehension about the future.

When asked about their concerns around getting older, many feared experiencing more frequent hypoglycaemic episodes (hypos). This is where blood glucose levels drop too low, causing dizziness, confusion and, if untreated, more serious complications. A major worry was the loss of important hypo warning signs, known as 'hypo unawareness', making it harder to recognise and treat episodes in time. Research has shown this is a widespread issue among older adults with T1D, with many unaware they are experiencing hypos at all⁴. One study of people over the age of 60 found that over half of participants spent at least an hour a day in the hypoglycaemic range.⁵

Studies also show that older people with diabetes are more likely to experience multiple health conditions and frailty, increasing their risk of serious issues like disability and even early death⁶. Our market research echoed these concerns. There were widespread fears around the increased risk of developing additional health conditions as people lived longer with T1D. Known complications associated with the condition include neuropathy, sight loss and cardiovascular problems. Alongside these worries, people were uncertain about how they might manage these complications as they aged.

For women, there was additional concern around the impact of hormonal changes during menopause and how this would further complicate blood glucose control.

But physical health was only part of the picture. Participants also expressed a deep sense of the mental load that comes with T1D. Words like 'struggling', 'burden' and concerns about 'coping' were repeated throughout the research.

Members of the online community were asked to 'sort' aspects of their life with type 1 to define what concerned them. Of this group, 75% said they were very concerned about long-term health effects of T1D, while 63% were particularly worried about the potential loss of independence in managing their own care as they got older. The impact on mental health and wellbeing was a concern for 88% of respondents, who described it as either 'very concerning' or 'a little concerning'.

People worried about their ability to maintain the level of control they had managed over their diabetes so far and how future physical or cognitive decline could compromise this. The prospect of losing the ability to make informed decisions and manage their condition independently was a source of real fear.

- Older adults with type 1 diabetes often not aware of hypoglycemia Endocrine Society Hypoglycemia and Glycemic Control in Older Adults With Type 1 Diabetes: Baseline Results From the WISDM Study Journal of Diabetes
- Science and Technology, Sage Journals Multimorbidity, Frailty and Diabetes in Older People–Identifying Interrelationships and Outcomes Journal of Personalized Medicine, PMC



"We've all heard a story of someone that wasn't allowed any breakfast because the nurse wasn't there, so she couldn't give him any insulin. We don't want to be there." "They wouldn't let me have my insulin pens. They took it all away from me. It was like I was talking to people from another planet." "It's one thing giving an injection of insulin, it's another thing being in charge of someone's pump and knowing how that works as well."

Hospital admission

As people get older, their health needs become more complex, and they are increasingly likely to need a stay in hospital. For those growing older with T1D, a hospital stay brings added risks and anxieties. When dealing with multiple health concerns, the need for specialist diabetes care becomes even more critical, yet it is often lacking in hospital settings. These gaps persist despite the *Getting It Right First Time (GIRFT)* recommendations, which call for every hospital to have a specialist multi-disciplinary diabetes inpatient team⁷. These teams are essential to ensure patient safety and provide proper monitoring and management during hospital stays.

Of the respondents from our market research who had recently been in hospital, almost 7 in 10 (68%) said they didn't have access to a diabetes specialist nurse or member of the diabetes team during their stay. Without this specialist care, people were left in a stressful environment trying to self-advocate on busy wards with staff often lacking the necessary knowledge of the intricacies of T1D. This added stress was layered on top of the reason for their hospital admission.

For many participants, one of the biggest sources of anxiety was the potential loss of control over their own diabetes management while in hospital. Fears included staff's lack of understanding of T1D and how it interacts with other illnesses and injuries and poor past experiences with inadequate care. A major concern was the ability to manage their own insulin while on a ward.

People described the harrowing challenges they'd had in accessing their insulin while on hospital wards. For example, some experienced having their insulin restricted to an arbitrary number of units or it being locked away out of their reach. People told us about staff being unavailable or unwilling to assist with hypos. One participant witnessed a patient in another bed arguing with nurses about the need for more insulin which was locked in a cupboard. She explained:

"Just before she was eating, she'd go, 'No, I need X amount of units,' and they'd go, 'No, you can only have this unit while you are on this ward.' She wasn't getting the correct insulin, the bloods were going high, and they're going, 'No, you're not having any more insulin.'"

The person sharing this story ended up stepping in, advising staff that the patient could fall into life-threatening diabetic ketoacidosis (DKA) if she didn't receive the appropriate insulin dosage. Another participant in our study said he'd resorted to hiding his spare insulin pens after staff had insisted on locking them in a medical cupboard and restricting his usage.

As diabetes technology and management options continue to advance, they can add complications to hospital care. Staff are faced with a condition requiring a broad spectrum of knowledge. This understanding is vital, particularly when patients are unable to advocate for themselves.

 7 'Patient safety must be at forefront of post-COVID care' says GIRFT diabetes national report - Getting it Right First Time, NHS England

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"Menopause information matters to every female living with diabetes."

"One of the GPs said I couldn't get HRT. When I asked why, they said 'Oh, you can't get this because you're a higher risk of heart disease [because of type 1 diabetes].' "It's a desert in terms of information. Everyone seems to get batted backwards and forwards between the diabetes team and the GP. Nobody will take ownership of treating the menopause." "There's lots on pregnancy, but pregnancy lasts nine months. The menopause...[is] a much bigger chunk of our lives."

Women's health and menopause

The symptoms of menopause and perimenopause can have a significant impact on women's physical and mental health, affecting everything from sleep and energy levels to mood and cognitive function. As the levels of female hormones, oestrogen and progesterone fall, it can be harder to manage blood glucose levels and insulin can start to work less effectively.

Many women in our market research said a lack of information left them completely unprepared for what to expect during the menopause. Because T1D is a condition that relies heavily on self-management, this gap in support poses a serious health risk. Women described feeling isolated as they navigated the impact of physical and emotional changes alone, with little guidance from healthcare professionals.

Having T1D often made getting a menopause or perimenopause diagnosis more complicated and created additional barriers to accessing treatment and support. Women who were able to access treatments like hormone replacement therapy (HRT) often found it beneficial in stabilising their blood glucose levels and improving their overall diabetes management.

However, many experienced significant difficulties in accessing treatment. Participants reported being told by medical professionals that certain medications, including HRT, were not suitable for people with T1D. Often, they weren't given a clear explanation or offered alternative options.

Without adequate medical support, many women felt they had no choice but to seek information and advice elsewhere. They joined support groups or online forums to hear from others going through similar experiences.

When going for appointments, women described feeling disregarded by medical staff and having to be forceful to get their voice heard. Preparing for appointments often meant equipping themselves with detailed information, ready to advocate for their own needs. For many, this struggle characterised their entire journey with T1D, a constant battle to be listened to and understood.

Some women contrasted their experiences of menopause with the support they received during pregnancy, highlighting the stark differences. During pregnancy, there was a well-established support system in place, with clear care pathways and specialists who understood diabetes and gestational diabetes.

Women felt reassured, supported and had access to professionals who could answer questions and help manage anxieties around complications and risks. In sharp contrast, their experiences of menopause were marked by confusion and isolation. Without that same level of care, women felt alone, stressed and at a complete loss for how to manage their symptoms alongside T1D. The effects of this lack of support were profound, eroding trust in medical professionals and exacerbating the day-to-day challenges of living with T1D.



"When I was diagnosed, I wasn't expected to be alive now. And here we are, and strong and fit. But then you think, where are the complications? They've got to come at some point." "I feel very concerned about ageing and my diabetes care. I'm constantly checking the lifespan of diabetics. It's not helping my mental health." "I've seen some horrendous things, from ulcers to amputations, so that does worry me. [When I get] pins and needles, I'm thinking, 'Is this progression?' and your mind races." "One of my main issues is living on my own and maybe not having the regular care [or] somebody looking out for me and making sure that I'm doing it properly."

Older age and retirement

The experience of retirement for respondents to our study was mixed. For many, retirement brought the opportunity to lead active lifestyles, pursue hobbies and enjoy travel. For those diagnosed with type 1 at a young age, reaching retirement age often came with a sense of surprise, given they'd been told their lives would be limited by their condition.

Despite the positives of retirement, the prospect of getting older was a source of apprehension and nervousness for almost 8 in 10 people (77%), especially around their ability to manage their diabetes as their cognitive and physical abilities decline. A key concern was maintaining autonomy to manage their diabetes for as long as possible. Respondents told us that no one else could manage their diabetes like they do. There were feelings of a lack of trust in medical or care staff to manage this on their behalf.

People said the only hope was technology and the potential of hybrid closed-loop (HCL). These systems, which automate aspects of blood glucose management, offered a degree of reassurance for those worried about losing the ability to manage their condition independently. However, there was also a strong belief that without access to the right technology, their health and quality of life would deteriorate if their diabetes care were passed to others.

Alongside inevitable fears of ageing, there were specific concerns linked to living with T1D, particularly around the risk of developing serious complications like neuropathy, eye problems and amputation.

There were concerns about the risk of developing other autoimmune conditions. These fears added to the already high levels of anxiety about ageing among this group. The concerns were not unfounded.

Evidence shows that both ageing and living with one autoimmune condition increases the risk for developing another^{8/9}. This anxiety was made worse by a lack of confidence that people would receive appropriate and informed care if their health deteriorated.

For those living alone, there were additional fears around accessing support in an emergency. Around 4 in 10 survey participants (39%) shared that they had co-existing health conditions, such as neuropathy, arthritis, hearing difficulties, underactive thyroid and hip problems, which were often complicated by type 1.

Immunosenescence in autoimmune diseases- Autoimmunity reviews, ScienceDirect.

⁹ Type 1 Diabetes Mellitus and Autoimmune Diseases: A Critical Review of the Association and the Application of Personalized Medicine-Journal of Personalized Medicine, MDP



"I think you hear too many horror stories about people not being cared for well enough. I just don't trust it." "Each care home needs to have staff trained in dealing with type 1 and they need to be educated in the everchanging technologies that we use. Staff need to be available 24 hours a day, 7 days a week as there are no breaks or holidays away from type 1."

Care homes and care for older people

The anxiety of needing care or moving into a care home as you get older is something many people experience. But for people with T1D, there is the added stress and worry that care home staff may not have the necessary training or understanding of the condition.



People told us they were concerned about the lack of nuance and awareness among home staff when it comes to managing T1D, including understanding insulin ratios, carb counting, use of technology and individual variability. There was a widespread perception that care staff were more familiar with type 2 diabetes and believed that insulin was often administered in a 'one size fits all' way.

Some respondents had either worked in or visited people in care homes, and their fears were based on what they'd witnessed. People told us about care home residents being given incorrect insulin dosages or left waiting when they needed insulin. This was seen to be heightened by insufficient staff training.

Another significant concern was the lack of coordination between care homes and hospital diabetes or endocrine departments. People felt there was an absence of regular external checks, such as time in range assessments, and no advocacy for residents who might be unable to self-manage their condition, such as those with dementia.

As a result, many people believed that entering a care home would lead to a rapid deterioration in their health. This fear meant that for many, a care home was simply not seen as a viable option.

People caring for their older parents with T1D said they wanted to keep care within the family for as long as possible. They expressed a lack of confidence in care staff's ability to manage type 1 with the necessary knowledge and attention. The intricacies of the condition and different types of technology require specialised training and experience that people felt was often missing in care settings.

The well-documented pressures on the social care sector only fuelled this lack of confidence. People felt that care homes already struggled with a lack of resources and expertise, let alone the complex needs of residents with T1D. It was felt that the scale of the work involved to increase the professional skills and expertise of staff to support people with type 1 was doubtful. This reinforced the importance of maintaining autonomy over their own diabetes management for as long as possible.

"One of the advantages I have found is that my blood sugar does not peak and trough in the way that it did before, which has to be beneficial for my memory and general brain function." "I'm very grateful that we've got the CGM now because years ago it was so difficult. It was all guesswork." "I've gone from being about 65% time in range and now average about 85%. I've never had that before. I actually feel as close as you can to being non-type. It has given me my life back in terms of quality."

Using technology

T1D technology has undergone significant advancements in recent years. Devices can help ease the daily demands of managing type 1 and support people to stay within healthy blood glucose levels. The development of these technologies means older people can benefit from innovations like automatic insulin dosing and closer monitoring.



However, the uptake and experience of using these tools can vary widely, influenced by access, awareness and individual confidence with technology.

Some respondents in our study revealed how transformative technology has been for them, describing how "everything changed" for the better in their T1D journey with the development of technology to support them. Technology offered a sense of security, greater control and an improved quality of life¹⁰. For those using continuous glucose monitors (CGM), a wearable device that measures glucose levels in real time, this was a vital step forward. CGMs reduced the guesswork of diabetes management, providing immediate feedback and enabling better, more informed decision-making.

For older people using a hybrid closed loop (HCL) system, which takes readings from a CGM to tell a pump how much insulin to deliver automatically, the impact was profound. Respondents described feelings of "relief" and a "weight being lifted" as the system alleviated much of the constant mental load of managing T1D. These experiences reflect the findings from the NHS HCL pilot study we funded, where over 94% of participants reported that HCL had a positive impact on their quality of life. It is vital that access to this technology is equitable across all age groups, particularly for older people, where HCL has the potential to transform diabetes management and ease the daily burden.

When it came to conversations about where people learned about technology options, the internet and online forums (52%) were closely followed by diabetes specialist nurses (48%) and support groups specifically for those with T1D (39%). Diabetes specialist nurses were seen as crucial, particularly when it came to providing practical and tailored advice on using technology.

While some people had reservations about the pressure of ongoing monitoring, the dominant theme regarding technology was overwhelmingly positive. Respondents shared how technical advancements had improved their day-to-day lives, reducing anxiety and offering reassurance. Multiple people referenced the improvement in their sleep and sleep quality.

Technology also made life feel more like it was before their T1D diagnosis. It provided comfort, stability and the management of the condition took up less of their time and attention. For people caring for their parents, technology provided an additional layer of support. Most of those involved in our market research weren't full time carers and often juggled caring with work and family. Technology offered them the ability to monitor their loved one's glucose levels remotely, giving them peace of mind when they couldn't be physically present. The ability to track data in real-time meant they could intervene when needed and ensure their parent's condition remained stable.

¹⁰ Hybrid Closed-Loop Therapy in Adults With Type 1 Diabetes and Above-Target HbA1c: A Real-world Observational Study - Diabetes Care, American Diabetes Association "I think it's like Dr Google. You don't know what information you are getting. So it's all very well saying the doctor's not good enough, or the practice is not good enough, but is going on to Google any better? Are you really going to get sound information?" "[My diabetes specialist nurse is] amazing, but she doesn't have diabetes. So, she can give me the science, the background behind it. But the way of living an experience of these things, I've always found that peer support is more helpful than healthcare support."

Access to information

Access to accurate, timely information is vital for people with T1D, helping them manage their condition effectively and minimise longterm complications. Our market research highlighted the three main ways respondents accessed information: through medical professionals, the internet and peer support from others with T1D. For many, it was a case of using a combination of these methods, depending on what they need and when.

The advice of medical professionals was viewed with varying levels of trust and confidence. Some participants shared positive experiences, praising GPs and diabetes teams for their attentive and personalised care. These trusted advisors were seen as invaluable in helping people manage their condition. However, others reported feeling like a number, describing rushed appointments and a lack of meaningful dialogue. This inconsistency in care often left people feeling unsupported and frustrated.

It's important to note the differing levels of reliance people placed on medical advice. Those who didn't automatically seek it cited several reasons. Some felt that medical information was too formal or detached from their lived experience. Others had negative or even traumatic interactions with medical staff and were reluctant to rebuild trust. Some believed their local GP or diabetes teams simply didn't have the time to engage in the in-depth conversations they needed.

The internet emerged as a widely used and easily accessible source of information. It offers immediate access to a vast array of resources on post-diagnosis management, technology, day-to-day tips, and responses to specific symptoms or reactions. Some participants appreciated being able to search for information during anxious moments, like sleepless nights, or to find answers without waiting for medical appointments. However, the unregulated nature of online health information was a recurring concern. Participants acknowledged the risks of misinformation and stressed the importance of being able to distinguish between credible and unreliable sources.

When it came to emotional support, the value of peer connections was unmatched. People turned to both in-person groups and online communities to share experiences and seek advice from others living with T1D. Peer support was often viewed as more relatable and practical compared to the clinical knowledge offered by healthcare professionals.

In-person support groups provided opportunities for social connection, with guest speakers often invited to share expert insights. Unfortunately, the availability of these groups varied, leaving some people feeling isolated and without local support networks. The internet also played a crucial role for carers supporting parents with T1D. Many carers reported a lack of support, so they turned to online searches to fill knowledge gaps. For carers learning to manage their loved one's diabetes as their independence declined, the pressure to learn quickly and advocate effectively was immense. Ensuring they access accurate and practical information is essential, as the quality of care they provide directly impacts the health and wellbeing of their parent.





Recommendations

The real world experiences of those ageing with T1D have given us insight into the systemic failures of the health and social care system. The following recommendations aim to address these failings.



¹¹ 'Patient safety must be at forefront of post-COVID care' says GIRFT diabetes national report - Getting it Right First Time, NHS England



General support Care Build on existing guidance to establish Ensure diabetes specialists provide clear, a clear, coordinated national strategy up-to-date information about available for managing T1D in care homes, technology, recognising its critical role in ensuring individuals receive safe, easing T1D management, particularly as consistent, and person-centred care people age. when they can no longer self-manage. Introduce Care Quality Commission Expand access to diabetes technology, (CQC) guidelines requiring all care acknowledging its potential to staff, both in care homes and the significantly improve care for older community, to be trained in T1D people. management, including safe and accurate insulin administration.

3

Implement personalised, regularly updated action plans for individuals with T1D, ensuring seamless care if they become unable to self-manage.

Conduct further research to evaluate the usability, clinical benefits, and potential adaptations of HCL systems for individuals with reduced cognitive function.

Summary

This report highlights the stark reality of ageing with T1D. It's a time marked by increasing physical and cognitive challenges, gaps in medical support and care, and widespread fears about the future. While research and clinical focus have centred on diagnosis and early management, little has been done to address what people's needs are decades down the line. This means there's a generation navigating the unknown, often without the care and guidance they desperately need.

One of the most alarming findings of our market research is the lack of preparedness in hospitals and care settings. People with T1D described harrowing experiences including insulin being locked away and dosages denied, meaning they had to self-advocate urgently for their care.

Meanwhile, concerns over the capability of care home staff to manage a condition as complex as T1D raise serious questions about the future of diabetes care.

Women report feeling abandoned by a system that's failed to acknowledge the impact of the menopause on their blood glucose control.

This makes this stage of their life a time of confusion and isolation, leaving women struggling with their health without any support. We know that technology is key to transforming care with lifechanging innovations that reduce the daily demands of managing the condition.

But access remains uneven and many older people are left without the technology that could significantly improve their quality of life.

But, solutions exist and policy makers, healthcare professionals and decision-makers must listen to older people with T1D and implement urgent change.

We need mandatory training for all medical staff on T1D with every inpatient having access to diabetes specialists during their hospital stay.

Outside of hospital, diabetes technology must be prioritised as a tool to support older people with self-management. Women must no longer be left to navigate the impact of menopause alone. We need more clinical research on the impact of the menopause on T1D, updated guidelines and better-informed healthcare professionals. And for those people who can no longer self-manage at home, national standards and guidelines should be followed to make sure their safety within care homes.

At Breakthrough T1D we are determined to shift how health and social care provides for people living with T1D. This report is the start of our work: to change the future of T1D and ageing so that people with T1D can live longer, healthier lives.





About Breakthrough T1D

We are Breakthrough T1D, the leading global T1D research and advocacy charity, we help make everyday life better while driving toward cures. Today, we are opening doors that were once closed by T1D diagnosis. We do this by connecting the brightest minds and investing in the most promising research, campaigning for access to treatments and technologies, and supporting the T1D community. Tomorrow, we will make this condition a thing of the past.

Find out more: www.breakthrought1d.org.uk

Recruitment of participants

As well as recruiting through our own channels, we also spoke to people who weren't already part of our network. This made sure we had a diverse range of respondents.

With thanks

The research and full report this document is based on were completed by M·E·L Research, a market research consultancy commissioned by Breakthrough T1D to carry out the work.

For information, support, and more on how to get involved, visit: **breakthrought1d.org.uk**

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