

Type 1 diabetes through the challenges of dementia: case reports

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Abstract

Medical advances continue to improve the life expectancy of people living with type 1 diabetes (T1DM). As this population grows older, they will increasingly encounter the challenges of ageing, including dementia. Many people living with T1DM are concerned about how their diabetes might impact their care needs, including their ability to self-manage. This case series aims to highlight some of the challenges that arise in the care of older adults with T1DM and dementia, including the transitioning of care to carers, community nursing teams or residential care. Since the population of older adults with T1DM is expected to continue to increase, researching ways to improve the care of older adults with T1DM should remain a key priority.

Introduction

The last century has seen dramatic medical and technological advances which have facilitated sustained increases in the life expectancy of people living with type 1 diabetes (T1DM).^{1,2} This ageing T1DM population will increasingly encounter the challenges of ageing, including frailty and/or dementia, which can both complicate diabetes management. There is little research addressing the needs of older individuals with T1DM who are facing these challenges.³ This may be in part because today's older adults are the first to be diagnosed during a time when survival to old age in large numbers has become possible.

The approach to the management of older adults with T1DM with physical or cognitive impairment derives from evidence in

type 2 diabetes (T2DM). Guidelines promote gradual relaxation of glucose targets as frailty progresses to prioritise the avoidance of hypoglycaemia.^{4,5} Medications with a high risk of hypoglycaemia, such as insulin or sulfonylureas, are replaced where possible, and higher glucose levels are accepted. This approach recognises that hypoglycaemia in older adults is associated with an increased risk of falls, fractures, hospitalisations and greater all-cause mortality while acknowledging the diminishing returns derived over time from tight glycaemic control in someone who has a limited life expectancy for other reasons.⁶ However, the application of these guidelines in T1DM presents issues as management necessitates insulin. Therefore a medication with a high risk of hypoglycaemia must be used, and relaxation of glucose targets in T1DM could increase the risk of diabetic ketoacidosis (DKA), a much rarer complication of T2DM.

Research into how best to manage T1DM in older adults is of importance to the diabetes community, as evidenced by a recent workshop by Diabetes UK.⁷ However, recognition of the specific challenges faced in the management of T1DM in older adults is rarely presented in the academic literature.⁸ The aim of this case series is to highlight some of the challenges faced by clinical teams in the management of patients with both T1DM and dementia, in order to stimulate debate and further research. It was felt that a case series would be the best way of illustrating the unique challenges faced by older adults, with each case highlighting a different aspect of care provision.

Case 1: Diabetes technology and the onset of dementia

Case 1 is a 69-year-old woman, diagnosed with T1DM at the age of 35. She was managing independently on stand-alone insulin pump therapy (Roche Insight pump) with continuous glucose monitoring (CGM), with her HbA_{1c} consistently between 60mmol/mol and 65mmol/mol. At a diabetes review in November 2022, suspicion of cognitive impairment emerged and this was corroborated by the family. A Montreal Cognitive Assessment score was 23/30 (mild impairment), and a referral to the memory assessment clinic was made. When the Insight insulin pump warranty was due (and it became evident that the Insight pump was no longer going to be manufactured), an attempt was made to switch to another pump, but the patient struggled to make the transition. After multidisciplinary team

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discussions involving the patient, it was decided, after much debate, to let her continue to use the out-of-warranty pump with which she was already familiar.

She was able to self-manage her diabetes until the combination of her husband's death, excess alcohol intake and a stroke led to further cognitive and physical decline. She began to experience falls and was eventually admitted to hospital with confusion and DKA. It became clear that she was no longer able to manage her insulin pump. The pump was discontinued and she returned to insulin pens, with nurse supervision, as an inpatient. A diagnosis of dementia was subsequently established, and following further discussions involving the family, it was felt that she would be safest in a care home. She was discharged to a care home in December 2024.

Case 1: Discussion

It remains impossible to escape the fact that successful self-care of T1DM relies upon the sound judgement of the person managing it. This is true even of Hybrid Closed Loop (HCL) therapy, where National Institute of Health and Care Excellence (NICE) guidance states that the user must be able to operate it.⁹ Through the onset of dementia, judgement can fluctuate or be lost altogether, with varying consequences. Some individuals might forget whether they have given insulin, leading to missed or repeated doses. For these people, Bluetooth-enabled smart pens, which can record insulin doses, can assist. For others, cognitive impairment can manifest as a loss of neural plasticity, defined as 'the capacity of the nervous system to modify itself, functionally and structurally, in response to experience and injury'.¹⁰ This might make transition between insulin pump systems more challenging. In addition, unexpected changes to usual routine can pose challenges, as outlined in this case. In such circumstances, it can become suddenly apparent that the person is struggling to self-manage their diabetes, with risk of hyper- or hypoglycaemia leading to hospital admission.

It could be argued that the use of an out-of-warranty pump is not part of standard practice. However, in this case attempts were made to use newer, in-warranty pumps. Due to her impaired cognition, the learning of a subtly different skill was not possible, and the decision was therefore between two difficult options: either return to insulin pens, which again requires re-learning of a skill, or continue to use an out-of-warranty pump with the associated risks. This was a difficult decision but may have lengthened this person's ability to live independently.

As it is so difficult to train a carer or loved one to manage someone else's T1DM, loss of the ability to self-care for T1DM can mean premature admission to residential care. Currently, individuals in this position who value independent living must balance the risk to their health of sub-optimal glycaemic control, including the risk of life-threatening DKA, and their desire to remain in their own home. Some people in this position may accept the risk and opt to remain at home.

The assumption that a care home or nursing-home can seamlessly adopt T1DM management is not necessarily true either. Concern has been raised about the management of

T1DM in residential homes, where staff may be more familiar with T2DM, which is much more common in older adults.^{4,11} This can lead to dangerous misconceptions about the timely need for insulin; the perception of risk of DKA; and the requirement for ketone monitoring. Further research and training are urgently needed among care staff as the T1DM population ages and increasingly require their services.^{12,13}

Rapid improvements in diabetes technology are on the cutting edge of what is possible, but this can pose problems for individuals with cognitive impairment, who are less able to adapt to change. Technology companies should bear this in mind while devices remain under development, incorporating considerate design (button size, size of screen, location of buttons on handset). Established technology should not be readily shelved, allowing ongoing management for older adults who have learnt how to use it but might struggle with learning something new.¹⁴

Case 2: Managing T1DM with once-daily insulin

Case 2 is a 66-year-old who has had T1DM since the age of three. She was living alone, established on a basal-bolus insulin regimen and confident with carbohydrate counting and insulin dose adjustments. No early-stage microvascular complications were present despite the long-standing diabetes.

She started to unexpectedly miss outpatient appointments, and was subsequently admitted to hospital in 2024 with DKA. The history suggested progressive cognitive decline, and her admission was attributed to missed insulin doses. After an unsuccessful attempt to teach her elderly neighbour how to administer insulin, a plan was made for district nurse administration of insulin on her discharge.

Community nurses could visit her only once daily, and a bespoke regimen of Humulin S alongside Tresiba was trialled to manage her diabetes. When the insulin was given by district nurses, her glucose levels varied significantly, with episodes of hypoglycaemia due to missed meals. Eventually CGM (FreeStyle Libre) was used. Data capture was only 37% and other systems including Dexcom G6 and Dexcom one were trialled with limited success. The little CGM data available confirmed sustained hyperglycaemia.

She was eventually admitted to hospital with severe hyperglycaemia after a further missed dose of insulin. During the hospital stay, she fell and fractured her pubic ramus, and she was diagnosed with Alzheimer's disease. A pre-discharge comprehensive geriatric assessment identified needs that warranted a care home placement.

Case 2: Discussion

NICE recommends a basal-bolus insulin regimen as the standard treatment for T1DM.¹⁵ Even if the basal insulin was administered during a mealtime, a person unable to self-manage their T1DM would anticipate requiring assistance three times a day, with the timing of visits coinciding with meals. A carer taking on this management would also need to know the person's glucose levels, have knowledge of acceptable glucose ranges, and know what action to take if levels are outside this range. They would

also need to be empowered to adjust insulin doses in response to carbohydrate intake. This assumes a significant level of responsibility for a spouse, let alone a neighbour. It is hardly surprising that this person's neighbour was unable to take on this role.

An alternative to the basal-bolus regimen is a twice-daily pre-mixed insulin, requiring two visits per day. The insulin dose is usually fixed, requiring a strict dietary intake of carbohydrates to prevent hypoglycaemia. If a meal is missed, there is little flexibility to adjust doses, increasing the risk of hypoglycaemia. For this reason, clinical guidelines recommend reserving this regimen as a last resort in older adults.^{16,17}

District nursing provision is highly variable, depending on geographic location. Some areas limit district nurse visits to one per day.¹⁸ This may be sufficient for the majority of people with T2DM, who can achieve adequate control on a once-daily basal insulin but, as described, older adults with T1DM require a minimum of two insulin doses per day.

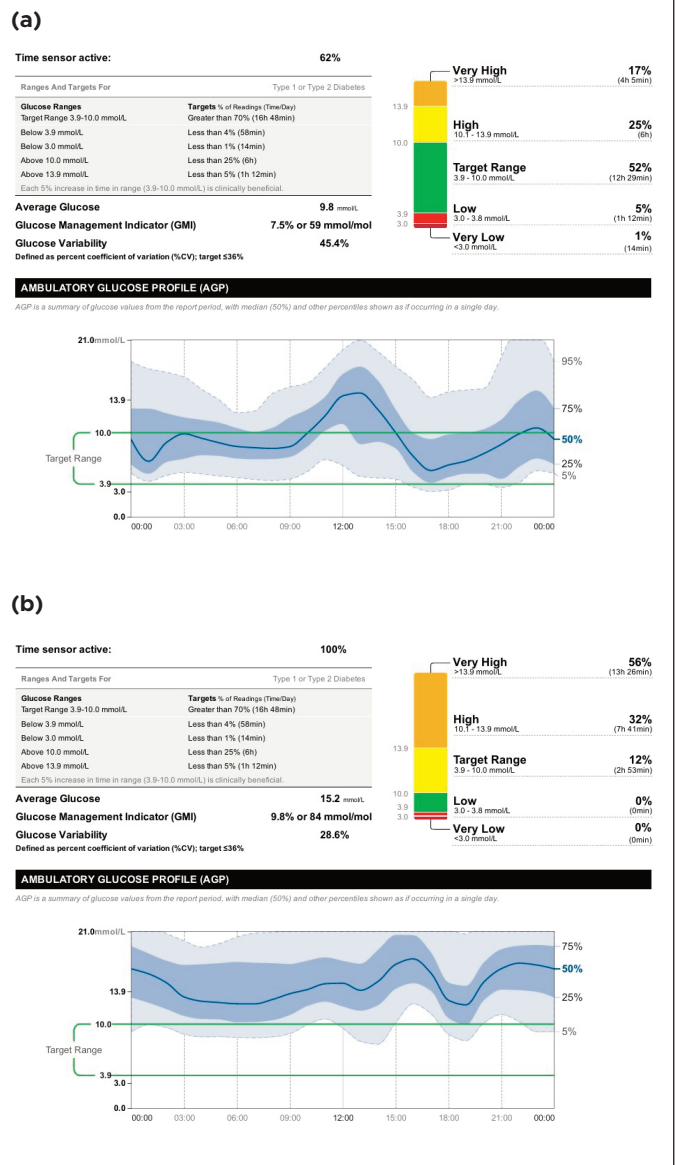
A bespoke "basal-plus" regimen was devised here in an attempt to manage her diabetes with once-daily visits. In this regimen, a rapid-acting insulin is given at the same time as the long-acting insulin to treat hyperglycaemia if present. Degludec (Tresiba) is a basal insulin which can last up to 48 hours, offering flexibility over the timing of the basal insulin administration. Humulin S is a rapid-acting insulin with a peak action of 30 minutes to one hour, and a duration of up to eight hours. This regimen is unlikely to maintain adequate glycaemia as it offers no meal-time dosing, with the rapid-acting insulin dose adjusted according to glucose levels rather than dependent on oral intake. It is therefore not surprising that this regimen did not succeed.

It is important that district nursing capacity is available for older adults with T1DM. Education about the increased complexity of T1DM among community nurses is needed. Communication is vital: individuals with T1DM should be made aware of what can be offered and the relative risks of different choices, such as community nurse administration compared to residential admission. All these options carry their own respective risks, and it is important that families are made aware of these to make informed decisions. It would be beneficial to have discussions about the aspects of diabetes care that matter most to people through the ageing process prior to the person losing the capacity to make these choices for themselves. Screening older adults yearly for cognitive impairment could aid with starting these discussions, while simultaneously helping to identify deteriorations in cognitive health. Clinic appointments should discuss subjects such as power of attorney, and individuals should be encouraged to appoint a trusted person so that decisions can be taken on their behalf should mental capacity be lost.

Case 3: Community sliding scale

Case 3 is a 78-year-old widow with T1DM diagnosed at the age of 49 and with background retinopathy as the only complication. Her medical history includes primary hypothyroidism and vitiligo. She was an early adopter of insulin

Figure 1. (a) Ambulatory glucose profile from 2022 on insulin pump therapy, highlighting frequent hypoglycaemia, and (b) Ambulatory glucose profile from 2024 on basal-plus regimen administered by district nurses. Hypoglycaemia avoidance has been prioritised to help avert further falls.



pump technology, in 1998. In 2019 she commenced CGM with an HbA_{1c} of 55mmol/mol.

At a diabetes review, CGM data revealed percentage time below range (%TBR, <3.9mmol/L) of 6%, and percentage time in range (%TIR, 3.9-10mmol/L) of 52%. She was using frequent correction doses to maintain tight glucose control despite encouragement from clinicians to relax control (figure 1a).

She began to miss appointments in 2021 and was later admitted to hospital following a road traffic accident, secondary to severe hypoglycaemia. Progressive cognitive impairment became apparent, and concerns arose about her safety with the insulin pump. A further hospitalisation in May 2023 prompted transition back to insulin pens. In July 2023, after an

Table 1. Summary of recommended insulin dose adjustments based on pre-meal glucose levels

	Blood glucose level (mmol/L)	Insulin dose
Breakfast NovoRapid	4.0 – 11.0	2 units
	11.1 – 14.0	4 units
	14.1 – 17.0	6 units
	17.1 – 22	8 units
	>22	10 units
Evening NovoRapid	4.0 – 11.0	0 units
	11.1 – 14.0	0 units
	14.1 – 17.0	2 units
	17.1 – 22	3 units
	>22	4 units
Daily Tresiba	N/A	8 units

accidental insulin overdose despite the use of a smart pen (Novopen 6), she was deemed no longer safe to administer her own insulin. The family found the responsibility of managing her glucose levels challenging, consequently involving district nurses. A basal-plus regimen was devised to accommodate twice-daily visits, with fixed basal insulin and rapid insulin doses varying according to glucose levels at the time of administration. Table 1 summarises the regimen, with an agreed target blood glucose level of 8 to 16 mmol/L

A stroke led to a further hospital admission, and a four times daily package of care was commenced on discharge. Despite this arrangement she continued to have frequent falls. A decision has now been made to allow glucose levels to run high to minimise hypo risk and help avert further falls (figure 1b).

Case 3: Discussion

A concept not discussed previously was ‘sliding scale’ insulin. This involves community nurses changing the insulin dose based on glucose levels (table 1). This approach more closely matches

traditional management, with users adjusting insulin doses according to factors such as oral intake and energy expenditure. This strategy was not discussed earlier because in some areas in the UK, community nurses do not take on cases which require a sliding scale. Where it can be done, it is believed to increase the chances of successful community management of T1DM. Where possible community teams should be encouraged to facilitate sliding scales for people with T1DM. Such a sliding scale could be facilitated by a personalised reference scale provided and adjusted by community diabetes teams.

Many professional carers working in care homes are not sufficiently confident to administer insulin, despite being able to give other medications. This is in part due to the risks associated with giving insulin, and the need for training for its administration. This can lead to frustration for community nurses, who must attend care homes to administer insulin. Carers should be empowered to give insulin where needed, but appropriate support and training will be required to facilitate this. This could release nurses to focus on other aspects of their role. Training is already available in many areas and is known as ‘Insulin administration training for non-registered practitioners’. However, the situation can be complicated by high turnover of staff in care settings and a reluctance to take on greater responsibility at low pay.

Another aspect of this case that is worth highlighting is the adoption of personalised glucose targets to prioritise the avoidance of hypoglycaemia.¹⁹ This practice is supported by guidelines which recommend relaxation of glucose targets through the development of physical or cognitive impairments.⁴ Relaxed glucose targets seem sensible in this case given the person’s propensity to fall, but there is little evidence to suggest what the adverse consequences of glucose levels that are higher than normal are in older adults with T1DM. Acutely there could be an increased risk of dehydration, infection and DKA with glucose levels that are elevated, and there may be a risk of the macro- and microvascular complications of diabetes over time. Ketone levels can be checked in urine or blood to assess whether the level of glycaemia is safe, or as an early marker of

Table 2. Key recommendations for the management of older people with type 1 diabetes and dementia or at risk of cognitive decline

Summary recommendations		
Annual review	HCP training	Technology development
Older adults should be screened for cognitive impairment	Care home staff should receive mandatory training on diabetes including the difference between type 1 and type 2 diabetes	Devices should incorporate considerate design features with older adults in mind (button size, screen size, location of buttons)
Where concerns arise, clinicians should discuss care preferences should cognition worsen	Community nurses should receive training on the additional considerations in older adults with type 1 diabetes	Established technology should continue to be supported to facilitate ongoing use by older people who might find transitioning to newer models more difficult
Discussions should identify trusted individuals who could aid decision making if mental capacity is lost. Individuals should be encouraged to appoint a lasting power of attorney	Carers should be supported with insulin administration tasks	
Individualised glucose targets should be agreed to account for frailty, cognition, and risk of hypoglycaemia	Education on appropriate use of ketone monitoring could help as an early indicator of illness	

infection. In circumstances such as this case, an assessment must be made about the relative risk of each of the hazards from hyper- or hypoglycaemia. Here, the risk of falling associated with hypoglycaemia was identified as the most important risk, and a decision was made to prioritise this over the risk of hyperglycaemia. This appears justifiable given the context.

A summary of the recommendations outlined in the discussion sections for each case is outlined in table 2.

The future

None of the solutions described ultimately provides an adequate solution to glucose management in people with T1DM and cognitive impairment. However, currently available technology could hold some answers. HCL can continually administer insulin in response to changing glucose levels detected via CGM. This could provide a means by which insulin could safely be administered in the community with minimal need for intervention from carers or community nurses. However, there are many obstacles that need to be overcome in its application in this setting, including:

- What would happen if the pump or CGM were to stop working or fall off?
- What might be the consequence if the user unknowingly changes settings on the device or administers insulin?
- What are the potential consequences of undetected hypoglycaemia or diabetic ketoacidosis?
- Is there an adequate training programme for carers to facilitate HCL use in the older adult population?

These are all valid concerns that need to be addressed, but it is clear from the cases described that the current status quo is not risk-free. This group is already at increased risk of acute diabetes-related emergencies, unplanned admissions and early admission to residential care, all of which come with costs for healthcare services. At the very least, HCL may make the situation no less risky, offer some respite for carers, and facilitate independent living for longer. There may also be a cost benefit associated with its use if hospital admissions are reduced and the need for residential care can be delayed.

There are several options that could be considered to adapt the technology for use in people with cognitive impairment, facilitated by community nursing teams. These include:

- **Co-administration of basal insulin**
This could avert DKA in the occurrence of a pump malfunction until the next carer visit. Those established on HCL systems would most likely still need daily visits to confirm compliance with pump therapy.
- **No meal announcements**
After a meal, the algorithm would gradually bring the glucose back to the target range. This would mitigate hypoglycaemia risk due to miscalculation of bolus doses.
- **Adjusted targets**
The HCL system could be set to achieve a higher glucose target to reduce risk of hypoglycaemia.
- **Restriction settings on the handset**
To avoid buttons being inadvertently pressed by the wearer.



Key messages

- ▲ The T1DM population is ageing, and more will face the challenges associated with ageing including dementia
- ▲ Dementia can complicate T1DM self-management and many will need to hand over this responsibility to a carer
- ▲ Harnessing currently available technology could enable individuals to remain independent for longer. Further research should look at how technology could be used safely in this setting

Remote monitoring

The ability for carers to monitor glucose from a distance, to ensure adequate functioning of HCL systems. Alarm thresholds could be set to guide when users might require intervention.

This approach will need collaboration from all relevant stakeholders, including technology companies, diabetes specialists, community nurses and the diabetes community. Research into how this technology could be harnessed to support independent living for older adults with T1DM should be a key priority for diabetes research.

There are significant challenges to overcome including who will be delivering the care and the upskilling of relevant staff. However, large numbers of people with T1DM are approaching old age, and if practical solutions are not found to overcome this issue, the challenges are likely to be even greater.

Conclusions

This case series describes the experience of older adults with T1DM who develop cognitive impairment. This includes the struggles arising from rapidly changing technology where user input is required, and the difficulties faced by patients and carers managing T1DM in the community.

Researching new ways in which this problem might be tackled is vital to meet the needs of older adults living with T1DM. It is possible that minor adjustments to HCL might hold the key to improving glycaemic control in this population whilst increasing people's independence. Even when this technology becomes available, the current multidisciplinary approach, which takes into account individual factors including frailty, cognition and the wishes of the person with T1DM and their family, will remain the cornerstone of management in this cohort.



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