The challenges of type 1 diabetes in older people

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Abstract
Over 200 000 people in England and Wales have type 1 diabetes. After the discovery of insulin, it became clear that people with diabetes had a reduced life expectancy and in the 1950s someone with type 1 diabetes might only expect to live until their sixth decade before they died from diabetic complications. Since then, longevity has increased and significant numbers are living into their eighth decade.

In 1985, Diabetes UK introduced the Nabarro medal for those who had lived with the condition for more than 50 years and, as evidence of increased life expectancy, the Macleod medal has been awarded since 2004 to survivors who have taken insulin for more than 70 years. In 2003, the Golden Years Study used data from 400 Nabarro medalists to provide important insights into the factors influencing longevity.

Age impacts on people’s ability to manage diabetes, particularly if accompanied by geriatric complications, such as dementia and frailty. There is a lack of research evidence on which to base guidelines for care in frail type 1 patients, but international diabetes organisations recognise the importance of this vulnerable group and have developed guidance for glycaemic targets and cardiovascular risk modification.

We put forward recommendations which recognise the need to individualise treatment. These emphasise the importance of providing education and training for professionals responsible for older people with type 1 diabetes to ensure that they can manage this condition with safety and understanding. Copyright © 2015 John Wiley & Sons.

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Key words
older people; physical frailty; cognitive impairment; glycaemic targets; standards of care

Introduction
Ten percent of people with diabetes have type 1 and over 200 000 people are currently living with the condition in England and Wales.¹ Despite the peak incidence in young people, this type of diabetes may present at any age² and new onset at the end of the ninth decade has been reported.³ However, most older people with type 1 diabetes will have had the condition for many years and thus accrued a wealth of experience in how to manage their own condition. In the past the diagnosis of type 1 diabetes was linked with a marked reduction in life expectancy and in 1985 the British Diabetic Association (now Diabetes UK) introduced the Nabarro medal, awarded to people with type 1 diabetes, who had lived for 50 years with the condition.¹ The medal recognised the achievements of Alan Nabarro, who had been diagnosed with diabetes in 1922 just as insulin was discovered and went on to live for 55 years, during which he championed the cause of people with type 1 diabetes. In 2014 Diabetes UK awarded 471 Nabarro medals, undoubtedly only a proportion of those eligible to receive the award, and the Lawrence (60 years) and Macleod (70 years) medals have been introduced as longevity increases.

Challenges of ageing with diabetes
The process of ageing inevitably leads to progressive losses which affect physical and cognitive performance and impact on diabetes management:
• Retirement may result in altered activity.
• Loss of muscle bulk and nerve supply (part of the process of ageing) makes exercise and sport more difficult and alters insulin sensitivity.
• Impaired sense of taste and dental problems may reduce food intake, leading to weight loss and potential malnutrition.
• Impaired vision may make self-management difficult.
• Loss of ability to drive may limit activity and increase a sense of isolation, risking depression and loss of motivation.

Increasing physical frailty and cognitive impairment contribute to the difficulties of insulin treatment. Insulin management has become more complicated, with emphasis on insulin adjustment and the introduction of...
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Review

The advent of new approaches to type 1 diabetes management, such as basal bolus regimens with ‘designer’ insulins, carbohydrate counting as a basis for insulin adjustment and insulin pumps, have provided more lifestyle freedom but have also put a greater burden of decision-making onto the person with diabetes. Although people with diabetes, like every other older person, should be encouraged to keep active to maintain physical strength, this is another situation which requires decisions about the insulin dose. Increased autonomy is a positive development but problems arise when a person becomes less able to make the day-to-day decisions required to manage their diabetes. The wealth of experience they have accumulated in diabetes self-management over the years cannot be passed on to carers, be they close family or professionals, and diabetes care becomes much more difficult. For people who have managed their diabetes carefully for many years, this loss of control (of both decision-making and of technologies such as insulin pumps and ‘smart’ blood glucose meters. Older people may struggle to cope with the complexity of dose adjustment. For decades after the discovery of insulin, the accepted way to manage type 1 diabetes was by strict control of diet, with carbohydrate distributed throughout the day to match a fixed dose of insulin. Those who were able to keep to this rigid regimen did well and some were, amazingly, even able to achieve good glycaemic control when taking a single injection of long-acting insulin daily. They accepted the inevitability of frequent hypoglycaemia and often depended on a partner to look out for the warning signs and help treat the hypos. Many people could not cope with the demands of such a regimented lifestyle, but those who could were likely to be rewarded with a reduced risk of complications and increased longevity.

As people age, they tend to become less flexible. This makes it easier to sustain the ingrained practices of years of living with diabetes, so people managing their diabetes using simple insulin regimens and fixed diets were able to maintain diabetes control as they became older. The advent of new approaches to type 1 diabetes management, such as basal bolus regimens with ‘designer’ insulins, carbohydrate counting as a basis for insulin adjustment and insulin pumps, have provided more lifestyle freedom but have also put a greater burden of decision-making onto the person with diabetes. Although people with diabetes, like every other older person, should be encouraged to keep active to maintain physical strength, this is another situation which requires decisions about the insulin dose. Increased autonomy is a positive development but problems arise when a person becomes less able to make the day-to-day decisions required to manage their diabetes. The wealth of experience they have accumulated in diabetes self-management over the years cannot be passed on to carers, be they close family or professionals, and diabetes care becomes much more difficult. For people who have managed their diabetes carefully for many years, this loss of control (of both decision-making and of

<table>
<thead>
<tr>
<th>Box 1. Identifying features of long-surviving patients with type 1 diabetes</th>
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<tr>
<td>• Reasonable (not necessarily ideal) control of blood glucose</td>
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<td>• High HbA1c levels</td>
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<td>• Low daily insulin requirements (‘insulin sensitive’)</td>
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<td>• Lower blood pressure</td>
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<td>• Microalbumin negative after 15–20 years of diabetes</td>
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Mortality data and increasing longevity

Since the discovery of insulin there has been a steady increase in life expectancy in people with type 1 diabetes due to a combination of improved patient education, advances in technology and risk factor modification. In Pittsburg USA between 1950 and 1964, those diagnosed with type 1 diabetes under the age of 17 years could expect to live to age 53, whereas if diagnosed between 1965 and 1980 the same age group had a life expectancy of 69 years. More recently, a study in Scotland compared life expectancy of people aged 20 years, with and without type 1 diabetes. They estimated that men with type 1 diabetes could expect to live a further 46 years, while those without diabetes were likely to survive for 57 more years. For women, the corresponding figures were 48 and 61 years. The largest percentage of estimated loss was related to ischaemic heart disease, but in people under the age of 50 the largest percentage of estimated loss was from diabetic coma or ketoacidosis. These findings are reflected in the National Diabetes Audit in England and Wales, 2012–13, which found that the mortality rate in young women was approximately seven times that of their non-diabetic peers. Thus, the overall upward trend conceals the fact that some groups continue to have a high mortality. Meanwhile, others exceed expectations by living for more than seven decades with type 1 diabetes, evidenced by the award of more than a hundred Macleod medals since their introduction by Diabetes UK in 2004.

Further evidence that not everyone with type 1 diabetes is living longer comes from a recent Finnish study. Life expectancy was measured in all people in Finland diagnosed with type 1 diabetes under the age of 30 years in two cohorts diagnosed from 1970–74 and from 1985–89. Standardised mortality ratio (SMR) in those diagnosed under the age of 14 was compared with those diagnosed aged 15–29 years. Twenty years after diagnosis, SMR fell in the early onset group from 3.5 (1970–74) to 1.9 (1985–89) while, in the older onset group, SMR in the same time periods increased from 1.4 to 2.9. Excess mortality in the late onset group was due partly to an increase in acute diabetic complications (diabetic ketoacidosis and hypoglycaemia) but was predominantly the result of alcohol-related conditions, both medical and psychological.

Factors influencing longevity: the Golden Years Study

Box 1 summarises factors influencing longevity according to the Golden Years Study. This study identified people with type 1 diabetes who had received the Nabarro medal between the years 1993–1996 to try to determine the characteristics which had led to their longevity. During these four years, 581 medals had been awarded (an average of 145 per annum) and 400 of these recipients took part in the study. This population is of course self-selected; the findings cannot be taken as representative of long-lived type 1 patients but they do provide interesting insights.

The mean ± SD age of the group was 68.9±5.5 years and the age of onset was 13.7±7.3 years. They had the following characteristics:

- Low prevalence of hypertension. Only 29% were taking anti-hypertensive medication, which would be unusual for any group in their seventh decade.
- Reasonable but not excellent control of blood glucose. Mean Hba1c was 7.6%, but this was not DCCT aligned and, given the normal ranges
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Quoted, the correct number is likely to be at least 1% higher.

- Lack of obesity. Mean BMI was at the upper limit of normal at $25.3\pm3.7\text{kg/m}^2$.
- High HDL cholesterol. Mean HDL cholesterol was 1.84±3.7mmol/L and 66% of this group had HDL levels above the reference range (0.6–1.6mmol/L).
- Relative insulin sensitivity. Mean total daily insulin dose in this cohort was 37.6±16.2 units and when corrected for body weight was 0.52 units/kg.

Of this cohort, 73% took insulin twice daily, 17% took three or more daily injections and 10% were only taking insulin once daily. This self-selected group of survivors had the following complications:

- Retinopathy: 43% had received laser therapy and 39% had cataract extraction; 2% were registered blind.
- Nephropathy: all participants provided a first-passed urine for urinary albumin–creatinine ratio (UACR). Microalbuminuria was present in 31% of men and 22% of women (threshold >2.5mg/mmol in men and >3.5mg/mmol in women). Macroalbuminuria (UACR >25mg/mmol) was present in 9% but the mean serum creatinine (125μmol/L) was within the reference range for a cohort of this age.

These findings from the Golden Years Study are supported by a recent review which examines the factors associated with longevity in type 1 diabetes.10 This discusses the following factors: glycaemic control, lipids, blood pressure, microvascular disease as a marker of survival and the influence of the metabolic syndrome, including insulin sensitivity. However, the best predictor of longevity is the age of one’s parents. In the Golden Years Study, both parents of those surviving 50 years with type 1 diabetes had lived to over 70 years, suggesting that genetic factors play an important role.

Although there is plenty of evidence that longevity is increasing, this may bring its own problems. Frailty, both physical and mental, is a feature of any ageing population but, for people with type 1 diabetes, this presents particular difficulties with regard to blood glucose management. We describe two contrasting real-life case studies.

**Case 1. Gladys**

- Age 84
- Type 1 diabetes since age 12
- Basal bolus insulin
- HbA1c: approximately 8% over many years. Meticulous attention to diabetes management
- Regular hypo–husband helps
- Below knee amputation in 2008 (small vessel vascular disease). Myocardial infarction (coronary stents) postoperatively
- No microvascular complications
- Became visually impaired secondary to macular degeneration. Impaired hearing
- Husband admitted to hospital and Gladys unable to manage without his support.
- Daughter (nurse) moved to be near her
- Admitted to hospital with UTI. Ward unable to support her to manage her diabetes. Insulin regimen changed by doctors against her wishes. Gladys very distressed because no longer allowed to make decisions about her diabetes. Wide variations in blood glucose and multiple (unsuccessful) changes of the insulin regimen by a variety of doctors
- Became depressed, withdrawn and stopped eating
- After many weeks in hospital, she was discharged to a nursing home with her husband
- Two weeks later, she collapsed and was admitted as an emergency but could not be resuscitated

**Case 2. Patricia**

- Age 67 years
- Type 1 diabetes since age 16 years
- Frequent episodes of severe hypoglycaemia, sometimes accompanied by seizures, over many years
- Cognitive impairment recognised in 2011
- Changed from basal bolus insulin to a range of fixed insulin regimens (none of them satisfactory)
- Increasing dependence on others to manage insulin and treat hypos
- Distress and anger at loss of independence
- Assessment in mental health unit
- Clinical commissioning group agreed funding for continuous glucose monitoring
- Could no longer be supported at home by husband and full-time carers. Refusing meals and refusing to let husband or carers give insulin
- Wide fluctuations in blood glucose with unexpected highs and frequent severe hypos
- Now funded for nursing home care with 1:1 non-qualified nurse 24 hours a day and continuing use of continuous glucose monitoring to alert staff to hypos
- Basal bolus insulin using fixed mealtimes doses and fixed corrections for blood glucose >18 and >24mmol/L
- Ongoing support from GP, dietitian and diabetes specialist nurse but fluctuations in blood glucose persist
- Continuing issues in the nursing home relating to diabetes knowledge of staff, decision-making, continuity of care and documentation

**Existing guidelines for diabetes in older people**

In recent years, a number of guidelines, position statements and reports from the US11,12 Europe13 and worldwide14 have advised on management of older people with diabetes, but these generally focus on type 2. The exception is the Position Statement of the ADA (American Diabetes Association) entitled ‘Type 1 Diabetes Through the Lifespan’.11 Understandably this
concentrates predominantly on children and young people with diabetes but includes a short section on Older Adults, which makes the following points:

- Not all older adults are alike – some may continue a rigorous regimen, while others require less stringent targets.
- Management is more challenging because of age-related conditions and diabetes-related complications.
- Be aware of insulin dosing errors, lack of meal planning and changes in physical activity.
- While hyperglycaemia causes dehydration and hyperglycaemic crises, hypoglycaemia is the major concern in older adults.
- Declining cognition contributes to hypoglycaemia unawareness and the ability to safely manage a hypo.

The ADA Consensus Report, ‘Diabetes in Older Adults’, is specifically concerned with type 2 diabetes since this is ‘overwhelmingly the most common incident and prevalent type in older age-groups’. However, the authors highlight a number of topics which are also relevant to type 1 diabetes, including:

- Vulnerability to hypoglycaemia.
- Comorbidities and geriatric syndromes including depression.
- Visual, hearing and functional impairment.
- Polypharmacy.
- Falls and fractures.

They stress the importance of shared decision-making between patient and professional wherever this is possible.

All these reports acknowledge the lack of research evidence to guide management of diabetes in older people, since the frail and elderly are generally excluded from studies. The number of elderly people with type 1 diabetes is increasing but still only represents a very small proportion of the total elderly diabetic population. Existing guidance is derived by extrapolation, either from evidence in younger people with type 1, or from older people with type 2. While it is reasonable to extrapolate from type 2 for blood pressure and lipid targets, glycaemic targets are more problematic since in type 1 diabetes insulin management is central to good care and not an optional extra.

### Box 2. Factors to consider when agreeing an individual HbA1c target

#### Standards of care

'Diabetes in Older Adults' sets standards of care as follows:

- Older adults who are functioning well physically and mentally may wish to aim for the same targets as younger adults.
- Targets may be relaxed and individualised for older adults with either physical or mental frailties but symptomatic hyperglycaemia should be avoided.
- Treatment of cardiovascular risk factors should take life expectancy into account.
- Screening for diabetes complications should pay particular attention to complications that would lead to functional impairment.

#### Glycaemic targets

For people with type 1 diabetes, the glycaemic targets should be agreed with the individual where possible, balancing the risk of hypoglycaemia against the potential benefit from a reduction in the risk of long-term complications. If this risk is judged to be small, the aim should be simply to avoid hypoglycaemia and symptomatic hyperglycaemia. Factors to be considered are shown in Box 2. However, older people with long-standing type 1 diabetes may find it difficult to relax targets because of a longstanding fear of complications and a corresponding acceptance of the inevitability of hypoglycaemia.

#### Hypoglycaemia

Elderly people are more vulnerable to hypoglycaemia. Age impairs the counter-regulatory response and hypoglycaemia unawareness is more common in the elderly. The risk of hypoglycaemia is increased by cognitive impairment and a history of severe hypoglycaemia increases the risk of dementia. Although these studies were carried out in people with type 2 diabetes, it is likely that the findings are relevant to type 1. Renal impairment and poor nutrition reduce the insulin requirement and increase the risk of hypoglycaemia. Both hypo and hyperglycaemia may increase the risk of falls in people with functional impairment.

#### Cardiovascular risk factor reduction

**Blood pressure.** Hypertension should be treated with a target of 140/80 (150/90 in those over 75 years). There is no demonstrable benefit from lowering the systolic BP below 140 and a diastolic BP less than 70 is associated with higher mortality.

**Lipids.** Statins are indicated for nearly all older adults with diabetes except those with short life expectancy. There is limited evidence for benefit of other lipid lowering drugs in any age group.

**Aspirin.** Aspirin is of proven value in secondary prevention of cardiovascular disease but the benefits must be balanced against the risk of bleeding in older people. The evidence for primary prevention is not strong and risks outweigh potential benefits.

#### Diabetes and dementia

The combination of type 1 diabetes and dementia presents a real challenge (see Case 2). The person affected often has a long history of type 1 diabetes and has been accustomed to self-managing. The insidious onset of dementia means that they may not acknowledge the problem. Insulin errors with omission or double-dosing may lead to high or low blood glucose levels. There may be reluctance to surrender control of diabetes to another person, with grieving or anger over their loss of independence. As dementia worsens, unpredictable and erratic eating may further complicate the problem. It is very unlikely that a carer will have the detailed knowledge to make the complex insulin management decisions required for a basal bolus regimen. The insulin regimen should therefore be simplified, relaxing glycaemic targets to avoid symptomatic hyperglycaemia and hypoglycaemia. Even this can be very challenging and the insulin regimen will need to be adapted depending on the capacity of carers to make decisions about dosage.
In recognition of the increasing prevalence of diabetes and dementia, two diabetes organisations – TREND-UK (Training, Research and Education for Nurses in Diabetes) and IDOP (Institute of Diabetes for Older People) – have collaborated to produce guidance for the management of diabetes and dementia for health care professionals and a leaflet for people with diabetes and their carers. These can be found on the Diabetes UK website.19,20

Managing diabetes in care homes

Diabetes UK has produced guidelines for management of care home residents with diabetes.21 These include the following recommendations:

- Each resident should have an individual care plan, based on an annual assessment of functional status (including vision), cognition and nutrition.
- Care homes should have policies in place for management of diabetes.
- Staff should have access to a diabetes education and training programme.
- The care plan should be agreed between the patient (or carer), GP and home care staff.

Despite the existence of these guidelines, an England-wide audit of care home residents carried out in 2012–1322 found some worrying deficiencies in diabetes care. Of the 49 000 residents audited, 10.4% were known to have diabetes, the majority with type 2. Forty-seven percent of staff were unaware of the Diabetes UK guidelines, 35% did not have access to education and training, and 37% of homes did not have a policy for management of hypoglycaemia. Sixty-three percent of homes did not have a nominated member of staff with responsibility for diabetes. Communication between the care home and primary care was poor, with only 36% of care homes holding copies of annual review reports. While this audit raises concerns about overall standards of care, it is particularly worrying for people with type 1 diabetes. It is likely that most homes will have very limited experience of their condition, and will not understand crucial aspects such as recognition and management of hypoglycaemia and the need to alter insulin at times of illness or reduced food intake.

The Care Homes Audit confirms the findings of a series of focus groups which sought the views of staff working in residential and nursing homes. Inability to access education and training was one of their greatest concerns.23

Conclusions

The number of older people with type 1 diabetes will certainly increase with time and we need to develop a strategy to ensure that long-term survival is not invariably accompanied by a fall in standards of care. In some ways the problems of the older generation are similar to those which clinicians and parents managing children with diabetes have been battling with for many years (e.g. unpredictable food intake or activity and varying insulin requirements). Improved technology, with pumps and continuous glucose monitoring (CGM), has certainly helped children and it is possible that, in the future, CGM could be employed to alert carers of older people to undesirably low or high blood glucose levels. In the meantime, it is crucial that carers and clinicians working with older people have the knowledge required to identify those at risk and to ensure safe management of this vulnerable group. This means simplification of insulin regimens, ability to recognise the early signs of hypoglycaemia, and knowledge of how and when to adjust insulin.

Recommendations

- In older people with type 1 diabetes, the annual review should incorporate screening for signs of cognitive and functional impairment.
- Inulin regimens should be simplified and glycaemic targets relaxed for those who are no longer able to make their own decisions.
- Nutrition should be reviewed and adapted to help avoid wide variations in the blood glucose.
- Strategies should be in place to enable early detection of hypoglycaemia.
- Carers, whether personal or professional, should receive education and training to provide the knowledge they require to assist with diabetes management.
- Care homes should have policies and care plans in place, in line with Diabetes UK guidelines, to ensure safe management of vulnerable older people with type 1 diabetes.

References