SPSO Scottish Public Services Ombudsman

The Scottish Public Services Ombudsman Act 2002

Investigation Report

UNDER SECTION 15(1)(a)

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Scottish Parliament Region: North East Scotland

Case ref: 201609022, Tayside NHS Board
Sector: **Health**
Subject: Hospitals / Clinical treatment / Diagnosis

Summary
Miss C complained about the care and treatment her late brother (Mr A) received from Tayside NHS Board (the Board). Mr A had type 1 diabetes with recurrent episodes of hypoglycaemia (when the level of sugar (glucose) in the blood falls below a set point) and a learning disability. Mr A, who had been a patient with the Board's diabetes service since he was a teenager, died unexpectedly aged 38 years.

Miss C complained there was a failure by the Board to appropriately assess and treat Mr A and to take account of how his learning disability affected his ability to manage his diabetes care.

We took independent advice from a consultant diabetologist.

Our investigation found that the management of Mr A's type 1 diabetes, given his learning disability, would have been challenging. However, in view of Mr A's recurrent often severe hypoglycaemic episodes and his apparent lack of awareness of his condition and how to manage it effectively, the Board should have focused on the management of his hypoglycaemia, listened to the concerns of Mr A's family and carried out a full assessment of Mr A's awareness of hypoglycaemia. The Board did not provide us with evidence that they did so.

We found that consideration should have been given to investigating whether there were any other possible underlying additional contributing conditions for Mr A's recurrent hypoglycaemic episodes as recommended in national guidelines and the recognised associations with other autoimmune diseases, given his family history of autoimmune disease.

While there had been attempts by the Board to change Mr A's insulin regime in the years prior to his death, which were unsuccessful, there was no evidence that consideration was given to trying other treatment or of a referral to other centres with more expertise in severe hypoglycaemia to try and address and mitigate against Mr A's recurrent severe hypoglycaemia.

Although it could not be definitely said that Mr A's death was as a consequence of a severe hypoglycaemic episode, it was possible given the circumstances of his unexpected death and as recurrent severe hypoglycaemia has been strongly linked as the potential basis for sudden death in persons with type 1 diabetes.

We considered the lack of action by the Board in their management of Mr A's diabetes represented a serious failure in his care and treatment and we upheld the complaint.

While we acknowledged and welcomed the remedial action the Board has taken on the need to better support people with diabetes and who have a learning disability, we considered this did not go far enough to address the root causes of the issues raised in this case. In particular, we were of the view the Board had not addressed the underlying clinical issues concerning the assessment and management of patients with type 1 diabetes and recurrent severe hypoglycaemia. We made a number of recommendations to address the failings in this case.

Redress and Recommendations

The Ombudsman's recommendations are set out below:

What we are asking the Board to do for Miss C:

What we found	What the organisation should do	Evidence SPSO needs to check that this has happened and the deadline
The assessment and management of Mr A's type 1 diabetes fell below a reasonable standard. There was a failure by staff to comply with national guidance, in particular, in relation to assessing and managing Mr A's hypoglycaemia. There were omissions in record-keeping in relation to documenting Mr A's hypoglycaemic awareness	Apologise to Miss C for the failure: • to reasonably assess and manage Mr A's type 1 diabetes, in particular, in relation to his hypoglycaemic awareness; • to properly take into account national guidance in their management of Mr A; and • in record-keeping in relation to documenting Mr A's hypoglycaemic awareness The apology should meet the standards set out in the SPSO guidelines on apology available at www.spso.org.uk/leaflets-andguidance	A copy or record of the apology By: 24 November 2018

We are asking The Board to improve the way they do things:

What we found	What should change	Evidence SPSO needs to check that this has happened and deadline
The assessment and management of Mr A's type 1 diabetes fell below a reasonable standard	The Board should have and apply a clear and standardised policy for the assessment and management of all patients with recurrent severe hypoglycaemia. Clinical case conferences should be held for challenging cases with hypoglycaemia (and/or challenges in care in those with a learning disability) as part of the Board's care quality programme	Evidence : • that the Board have a policy in place for the assessment and management of patients with severe hypoglycaemia which takes into account relevant national guidance; • the Board has carried out a review of the care, assessment and management of all patients with severe hypoglycaemia in line with this policy; and • clinical case conferences for challenging cases with hypoglycaemia are held and included as part of the Board's care quality programme By: 24 December 2018
There was a failure by staff to comply with national guidance, in particular, in relation to assessing and managing Mr A's hypoglycaemia awareness	Staff should be aware of and take into account in their clinical practice the Board's policy and relevant national guidance and standards in relation to the assessment and management of patients experiencing problems with hypoglycaemia. If in a particular case, the Board decides not to follow national guidance and standards, the reasons should be clearly documented	Evidence that this report has been shared with relevant staff and managers in a supportive way for reflection and learning By: 24 December 2018

What we found	What should change	Evidence SPSO needs to check that this has happened and deadline
There were omissions in record-keeping in relation to documenting Mr A's hypoglycaemic awareness	Records should be maintained in accordance with good medical and nursing practice	Evidence that this report has been shared with relevant staff and managers in a supportive way for reflection and learning By: 24 December 2018

Evidence of action already taken

The Board told us they had already taken action to fix the problem. We will ask them for evidence that this has happened:

What we found	What the organisation say they have done	Evidence SPSO needs to check that this has happened and deadline
The Board accepted that they had not met all of Mr A's needs throughout his time with the diabetes service	The Board said they had reviewed their approach to patients who have diabetes and a learning disability and their need to better support them	An update on the Board's diabetes and learning disability improvement plan and 'Diabetes Out There' project Evidence as to how patients are made aware of the diabetes managed clinical network website By: 24 December 2018

Who we are

The Scottish Public Services Ombudsman (SPSO) investigates complaints about organisations providing public services in Scotland. We are the final stage for handling complaints about the National Health Service, councils, housing associations, prisons, the Scottish Government and its agencies and departments, the Scottish Parliamentary Corporate Body, water and sewerage providers, colleges and universities and most Scottish public authorities. We normally consider complaints only after they have been through the complaints procedure of the organisation concerned. Our service is independent, impartial and free. We aim not only to provide justice for the individual, but also to share the learning from our work in order to improve the delivery of public services in Scotland.

The role of the SPSO is set out in the Scottish Public Services Ombudsman Act 2002, and this report is published in terms of section 15(1) of the Act. The Act says that, generally, reports of investigations should not name or identify individuals, so in the report the complainant is referred to as Miss C. The terms used to describe other people in the report are explained as they arise and in Annex 1.

Introduction

1. Miss C complained to my office about the care and treatment Tayside NHS Board (the Board) provided to her late brother (Mr A). Mr A had type 1 diabetes with recurrent episodes of hypoglycaemia and a learning disability. Miss C complained there was a failure by the Board to appropriately assess and treat Mr A and to take account of how his learning disability impacted on his ability to manage his diabetes care.

2. The complaint from Miss C I have investigated is that the Board unreasonably failed to provide Mr A with the appropriate assessment and clinical treatment in view of his reported symptoms (*upheld*).

Investigation

3. I and my complaints reviewer considered all the information provided by Miss C and the Board. This included Mr A's relevant medical records, the Board's complaint file, Mr A's General Practice records, and the post-mortem report on Mr A. We also obtained independent advice from a consultant diabetologist (the Adviser) on the clinical aspects of the complaint.

4. I have decided to issue a public report on Miss C's complaint. This reflects both my concerns about the significant and serious failings identified in Mr A's care and treatment and because I consider it is in the wider public interest in relation to the planning of patient diabetes care; in particular, for patients with a learning disability.

5. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked. Miss C and the Board were given an opportunity to comment on a draft of this report.

Complaint: The Board unreasonably failed to provide Mr A with the appropriate assessment and clinical treatment in view of his reported symptoms

Concerns raised by Miss C

6. Miss C said that Mr A was diagnosed with type 1 diabetes at age 15. She told us that Mr A had difficulty understanding how to manage his diabetes as a result of a learning disability and that she had acted as his carer. Mr A died unexpectedly at his home in September 2016, aged 38. The cause of his death was 'presumed complications of insulin dependent diabetes mellitus'.

7. Miss C said that she and her mother (Mrs B), constantly raised their concerns about Mr A's ability to manage his diabetes with the out-patient diabetes clinic (the diabetes clinic) which Mr A attended regularly. Miss C considered there was a failure to properly investigate Mr A's recurrent hypoglycaemic episodes and to carry out appropriate tests to ascertain the reasons for them. She also considered the diabetes clinic did not provide Mr A with appropriate support and treatment and failed to take account of how his learning disability and individual needs impacted on his ability to manage his diabetes.

8. Miss C considered that the support, education and information provided by the Board's diabetes service to Mr A had been 'poor'. She said that she and Mrs B's concerns about Mr A were not listened to and that she felt staff at the diabetes clinic regarded them both as being 'hysterical'.

9. Miss C said that Mr A had also regularly complained of stomach pain and had been advised to take pain medication. She questioned whether this treatment had been appropriate.

10. Miss C told us about how Mr A's death had greatly affected their family. In bringing her complaint to my office, she wanted to ensure that others, especially those with learning disabilities, did not experience what Mr A and their family had gone through.

The Board's response to Miss C

11. In response to Miss C's complaint, the Board said Mr A had been a patient with their diabetes service since he was a teenager.

12. The Board said they had met with Miss C and accepted they had not met all of Mr A's needs throughout his time with the diabetes service. They apologised and said the head of nursing, together with the learning disability team, the diabetes team and social work team would meet to discuss how they could improve the diabetes service for patients with additional needs. They also told her they would be working with health and social care teams to develop improvements to provide services which were responsive to a patient's individual needs. An improvement plan had also been developed and improvements in the diabetes service were underway. Miss C was not satisfied with this outcome and brought her complaint to the SPSO.

The Board's response to SPSO

13. The Board said that, as Mr A had been a patient of the diabetes service since he was a teenager and given the passage of time, a thorough investigation into Mr A's entire care and treatment from the diabetes service would be difficult. They told my office that the concerns raised by Miss C on behalf of herself and Mrs B had been taken very seriously and they had met with Miss C to discuss their concerns; a copy of the note of this meeting was provided to my office. They had offered their sincere apologies to Miss C and Mrs B and accepted that they had not met all of Mr A's needs throughout his time with the diabetes service.

14. The Board said that Mr A had been reviewed multiple times by both the diabetes specialist nurse and consultant team between 2008 and his death, with respects to his hypoglycaemia and insulin management. Attempts had been made to try basal bolus insulin regimens, which had been unsuccessful. This was discussed with Mr A in 2013, however the Board said he had declined to change regime.

15. As a result of the concerns Miss C had raised, the head of nursing had met with the learning disability, diabetes and social work teams to discuss how as a Board they could improve the diabetes service for patients with special needs. As a result of this, a diabetes and learning disability improvement plan had been developed with improvements underway. The Board provided my office with a copy of the plan.

16. The Board said that diabetes care for all people with type 1 diabetes had been evolving over the years. The current care available to patients newly diagnosed with type 1 diabetes was very different to the care experienced at the time of Mr A's diabetes diagnosis.

17. The Board said that in 2015 there was no routine access to continuous glucose monitoring. The funding for this would have been applied for on an exceptional basis. However, given the complexity of the device used at the time, it was felt that Mr A would not have been able to use this method effectively. Continuous glucose monitoring has been available since April 2017 after a national funding decision for technology in diabetes was made. There was also no access to flash glucose monitoring in 2015 and this currently remains the position, although the diabetes team had made an application for this.

18. The Board referred my office to the 'Diabetes Out There' project, which they said was part of the Board's transformation programme and consisted of paediatric and adult clinical teams which meet monthly to review actions/progress. The Board explained that the project's aim was to create a type 1 diabetes seamless service for patients up to the age of 25 years. The Board provided us with a copy of the transformation programme.

19. The Board also provided my office with a link to their diabetes managed clinical network website, which is a coordinated network of professionals involved in providing diabetes care across the region. Within this network, patients and professionals work together to continually develop and improve care. The Board said this site also provided patient and care information, with a link to the 'MydiabetesMyway' portal that patients were encouraged to register with, where they can access their diabetes test results and educational support to enable self-management of their diabetes.

Medical advice

Relevant Guidance

20. The Adviser referred us to the national guidelines relevant to this complaint and to the relevant sections of the guidance (see Annex 2):

- SIGN 116 'Management of diabetes'

- NICE guideline [NG17] 'Type 1 diabetes in adults: diagnosis and management'

21. The Adviser noted from the medical records that Mr A was diagnosed with type 1 diabetes when he was a teenager. He had a history of long standing documented recurrent severe hypoglycaemia episodes over a period of 13 years. It was recorded that Mr A had a learning disability and that he was under review by the learning disability nurse whilst living in supported accommodation. The Adviser said that it was also recorded that Mrs B felt that Mr A did not recognise 'hypos' (hypoglycaemia) and he was unable to control his diet. The Adviser said that the medical records detailed that another member of Mr A's family had type 1 diabetes and there was a family history of autoimmune disease.

22. The Adviser noted that Mr A's family had also raised concerns that he had complained about stomach pain.

23. The Adviser said that the management of recurrent severe hypoglycaemia in Mr A, a young man with a learning disability and difficulties with self-management, was clearly challenging. However, it did not appear that the issue of Mr A's recurrent hypoglycaemia had been focussed on by the staff who were involved in the management and treatment of his diabetes. In the Adviser's view, there was an inadequate assessment of the concerns expressed by Mr A's family about his recurrent hypoglycaemia.

24. The Adviser said there was a 13 year record of Mr A having recurrent often severe hypoglycaemic episodes which were not investigated for underlying additional contributing conditions, as recommended in national guidelines.

25. The Adviser told us that, based on the national guidelines and their recommendations, and the recognised associations with other autoimmune diseases, especially given the family history of autoimmune disease, it would have been appropriate to have assessed Mr A for coeliac, thyroid and Addison's diseases. However, the Adviser, from their review of Mr A's medical records, could see no record of such investigations having ever been carried out.

26. Although the Adviser noted that a case conference was held in 2007 to discuss Mr A, there appeared to have been no specific clinical aspects of Mr A's hypoglycaemia management raised and there was no evidence of a further review of Mr A's situation in a case conference setting thereafter.

27. The Adviser also told us that Mr A's insulin regime was changed in 2008 in light of challenges with his blood glucose control, however, this was stated to have not been effective. Despite Mr A's ongoing major recurrent hypoglycaemia, in particular, that he was experiencing further severe hypoglycaemia issues in 2014-15, there was no evidence of investigations to establish if there were secondary additional causes for this or of further efforts to review his insulin regime. The Adviser said this was a most challenging case involving a vulnerable young man and there were exceptional reasons to explore all avenues in order to try and address and mitigate against Mr A's recurrent severe hypoglycaemia.

28. The Adviser acknowledged that the Board did not have routine access to continuous glucose monitoring or flash glucose monitoring in 2015. The Adviser also recognised the challenges of the application of continuous glucose monitoring for Mr A even if funding had been secured on an exceptional case basis. Nevertheless, the Adviser told us that Mr A's recurrent severe

hypoglycaemia and the concerns which had been raised about this should have led to:

- an investigation of any underlying conditions Mr A might have had;
- a full assessment of his hypoglycaemia unawareness (notwithstanding the challenges of managing his insulin therapy, his diet and his documented learning disability); and
- regular reappraisal of options to address Mr A's recurrent severe hypoglycaemic episodes, including attempting to secure funding for flash glucose monitoring for investigative purposes on a single case trial basis; and referral to other centres with more expertise in severe hypoglycaemia, if options were limited. There was no evidence the Board did so.

29. In the Adviser's view, what had occurred was unequivocally a serious failure in care and potential treatment.

30. The Adviser also commented that in Mr A's medical records there was a diabetes clinic proforma document, with a section on hypoglycaemic awareness. However, despite it being documented that Mr A was having recurrent hypoglycaemic issues, this document had not been completed or evaluated formally and this was contrary to the national guidance which was available at the time.

31. Regarding the assessment of Mr A's reported stomach pain, the Adviser explained to us that, although unlikely, Addison's disease (which the Adviser considered Mr A should have been assessed for) can be associated with both recurrent hypoglycaemia and abdominal pain and was most usually associated with weight loss. The Adviser noted, however, from review of Mr A's medical records that his weight had increased between 2013 and 2015. The Adviser considered that, rather than expecting the diabetes team to investigate his stomach pain, it was reasonable to have expected Mr A's family's to have taken their concerns to his GP to pursue with gastroenterological and/or surgical input.

32. The Adviser told us that due to the condition of Mr A's body when he was found at home, it could not be determined that his death was a consequence of a severe hypoglycaemic episode. However, in the Adviser's view, it was a real possibility: taking into account the circumstances of Mr A's death and given that it is known that recurrent severe hypoglycaemia can be self-perpetuating unless corrected and has been strongly linked as the potential basis for sudden death in persons with type 1 diabetes.

33. While the Adviser considered that the Board had correctly reviewed their approach to patients who have diabetes and a learning disability, and their need to better support them, they had not addressed the underlying clinical issues relating to the assessment and management of patients with type 1 diabetes and recurrent severe hypoglycaemia. In the Adviser's view, the sad fatal outcome in this case made clear the need for the Board to carry out a review of the care, assessment and management of all patients with severe hypoglycaemia.

34. The Adviser explained to us that recurrent hypoglycaemia in a patient needs a formal diagnosis, assessment for secondary underlying causes, and a clear individualised management strategy. The Board should have a standardised policy for the assessment and management of all patients with recurrent severe hypoglycaemia, regardless of whether the patient has a learning disability. Staff should also be aware of and provided with updated guidelines and treatment programmes for the assessment and management of severe hypoglycaemia.

35. The Adviser also considered that clinical case conferences of challenging cases with hypoglycaemia and/or challenges in care in patients with a learning disability should also be part of the Board's care quality programme.

Decision

36. The basis on which I reach decisions is reasonableness. I consider whether the actions taken, or not taken, were reasonable in view of the information available to those involved at the time in question.

37. I have considered very carefully and taken into account the evidence Miss C and the Board provided, the additional medical evidence I obtained and the independent advice received from the Adviser. This advice, which I accept, is set out above.

38. It is clear that the management of Mr A's type 1 diabetes, given his learning disability, would have been challenging. However, in light of Mr A's recurrent often severe hypoglycaemic episodes and his apparent lack of awareness of his condition and how to manage it effectively, the Board should have focused on the management of his hypoglycaemia, listened to the concerns of Mr A's family and carried out a full assessment of Mr A's awareness of hypoglycaemia. The Board has not provided any evidence that they did so.

39. Consideration should have been given to investigating whether there were any other possible underlying additional contributing conditions for Mr A's recurrent hypoglycaemic episodes as recommended in national guidelines and the recognised associations with other autoimmune diseases, especially given his family history of autoimmune disease. Aside from a case conference in 2007, a change to Mr A's insulin regime in 2008, which was ineffective, and unsuccessful attempts to try basal bolus insulin regimens, there is no evidence that consideration was given to trying other treatment, or of a referral to other centres with more expertise in severe hypoglycaemia to try and mitigate against Mr A's recurrent severe hypoglycaemia.

40. I note that the Adviser also identified that a section on hypoglycaemic awareness in a diabetes clinic proforma document which was in Mr A's records had not been completed or evaluated formally, which is contrary to the national guidance. The Board has not given any reasons as to why national guidance was not followed.

41. I note the Adviser's view, that while it could not be definitely said that Mr A's death was as a consequence of a severe hypoglycaemic episode, it was possible given the circumstances of his unexpected death and as recurrent severe hypoglycaemia has been strongly linked as the potential basis for sudden death in persons with type 1 diabetes.

42. Based on the advice received I consider the lack of action by the Board in their management of Mr A's diabetes represented a serious failure in his care and treatment.

43. I acknowledge and welcome the remedial action the Board has taken on the need to better support people with diabetes and who have a learning disability. This is a positive and constructive reaction. That said, based on the advice received, I do not consider this goes far enough to address the root causes of the issues raised in this case. In particular, the Board have not addressed the underlying clinical issues concerning the assessment and management of patients with type 1 diabetes and recurrent severe hypoglycaemia.

44. I am also concerned that the Board do not appear to have:

- followed national guidelines (or given explanation as to why); and

- given consideration to exploring all possible avenues that might have been available in relation to trying to address Mr A's recurrent severe hypoglycaemia.

45. I am critical of the serious failings identified in Mr A's care and treatment. It is clear to me that there has already been a significant impact on Miss C and her family and I am mindful that learning of my conclusions is likely to add to their distress.

46. Having considered all of this, I uphold the complaint.

47. I have made recommendations to address the failings identified. These will be followed up to ensure the Board does, or has done, what they said they would as a result of my investigation. The aim of these recommendations is to prevent others experiencing what happened in Mr A's case and its impact on Miss C and her family. My recommendations are listed at the end of this report.

48. I am pleased to note that the Board have accepted the recommendations and will act on them accordingly. My office will follow-up on these recommendations. The Board are asked to inform my office of the steps that have been taken to implement these recommendations by the dates specified. I will expect evidence (including supporting documentation) that appropriate action has been taken before I can confirm that the recommendations have been implemented to my satisfaction.

Recommendations

Learning from complaints

The Ombudsman expects all organisations to learn from complaints and the findings from this report should be shared throughout the organisation. The learning should be shared with those responsible for the operational delivery of the service as well as the relevant internal and external decision-makers who make up the governance arrangements for the organisation, for example elected members, audit or quality assurance committee or clinical governance team.

What we are asking the Board to do for Miss C:

What we found	What the organisation should do	Evidence SPSO needs to check that this has happened and the deadline
The assessment and management of Mr A's type 1 diabetes fell below a reasonable standard. There was a failure by staff to comply with national guidance, in particular, in relation to assessing and managing Mr A's hypoglycaemia. There were omissions in record-keeping in relation to documenting Mr A's hypoglycaemic awareness	Apologise to Miss C for the failure: • to reasonably assess and manage Mr A's type 1 diabetes, in particular, in relation to his hypoglycaemic awareness; • to properly take into account national guidance in their management of Mr A; and • in record-keeping in relation to documenting Mr A's hypoglycaemic awareness The apology should meet the standards set out in the SPSO guidelines on apology available at www.spso.org.uk/leaflets-andguidance	A copy or record of the apology By: 24 November 2018

We are asking the Board to improve the way they do things:

What we found	What should change	Evidence SPSO needs to check that this has happened and deadline
The assessment and management of Mr A's type 1 diabetes fell below a reasonable standard	The Board should have and apply a clear and standardised policy for the assessment and management of all patients with recurrent severe hypoglycaemia. Clinical case conferences should be held for challenging cases with hypoglycaemia (and/or challenges in care in those with a learning disability) as part of the Board's care quality programme	• that Board have a policy in place for the assessment and management of patients with severe hypoglycaemia which takes into account relevant national guidance; • the Board has carried out a review of the care, assessment and management of all patients with severe hypoglycaemia in line with this policy; and • clinical case conferences for challenging cases with hypoglycaemia are held and included as part of the Board's care quality programme By: 24 December 2018
There was a failure by staff to comply with national guidance, in particular, in relation to assessing and managing Mr A's hypoglycaemia awareness	Staff should be aware of and take into account in their clinical practice the Board's policy and relevant national guidance and standards in relation to the assessment and management of patients experiencing problems with hypoglycaemia. If in a particular case, the Board decides not to follow national guidance and standards, the reasons should be clearly documented	Evidence that this report has been shared with relevant staff and managers in a supportive way for reflection and learning By: 24 December 2018

What we found	What should change	Evidence SPSO needs to check that this has happened and deadline
There were omissions in record-keeping in relation to documenting Mr A's hypoglycaemic awareness	Records should be maintained in accordance with good medical and nursing practice	Evidence that this report has been shared with relevant staff and managers in a supportive way for reflection and learning By: 24 December 2018

Evidence of action already taken

The Board told us they had already taken action to fix the problem. We will ask them for evidence that this has happened:

What we found	What the organisation say they have done	Evidence SPSO needs to check that this has happened and deadline
The Board accepted that they had not met all of Mr A's needs throughout his time with the diabetes service	The Board said they had reviewed their approach to patients who have diabetes and a learning disability and their need to better support them	An update on the Board's diabetes and learning disability improvement plan and 'Diabetes Out There' project. Evidence as to how patients are made aware of the diabetes managed clinical network website By: 24 December 2018

Terms used in the report **Annex 1**

Addison disease	a disorder that occurs in which the adrenal glands do not produce enough steroid hormones
autoimmune disease	where the immune system attacks healthy cells in the body
basal insulin therapy	long acting insulin therapy
bolus insulin therapy	fast acting insulin therapy
basal bolus regimen	a person with diabetes taking both basal and bolus insulin throughout the day
coeliac disease	an autoimmune condition affecting the small intestine caused by a reaction to gluten
continuous glucose monitoring	a method of glucose testing to measure the blood glucose level continuously which provides a warning if the blood glucose level is too high or low
diabetes mellitus	a medical name for diabetes
flash glucose monitoring	a method of glucose testing that constantly measures the blood glucose level
gastroenterological	relating to the diagnosis and treatment of diseases and disorders of the digestive system
hypoglycaemia	when the level of sugar (glucose) in the blood falls below a set point

insulin	a hormone made by the pancreas that controls the level of the sugar glucose in the blood
Miss C	the complainant
Mr A	the brother of Miss C and the subject of the complaint
Mrs B	the mother of the complainant and Mr A
plasma glucose level	the amount of sugar in the blood
subcutaneous insulin infusion	administration of insulin under the skin
the Adviser	a consultant physician who specialises in the treatment of diabetes who provided medical advice on the treatment provided to Mr A
the Board	Tayside NHS Board
thyroid disease	a disorder of the thyroid gland
type 1 diabetes	where the body's immune system attacks and destroys the cells that produce insulin

List of legislation and policies considered **Annex 2**

SIGN 116 Management of diabetes March 2010 (updated November 2017)

Section 2.1*:* adults with type 1 diabetes experiencing problems with hypoglycaemia or who fail to achieve glycaemic targets should have access to structured education programmes based on adult learning theories.

Section 2.2: this sets out specific programmes for those patients with significant problems with hypoglycaemia.

Section 5.5.4: 'thyroid and coeliac disease are reported to be increased in young people with type 1 diabetes compared with non-diabetic subjects. Both thyroid and coeliac disease may occur with minimal symptoms that may be missed during routine care. Young people with diabetes should be screened for thyroid and coeliac disease at onset of diabetes and at intervals throughout their lives.'

NICE guideline [NG17] 2015 Type 1 diabetes in adults: diagnosis and management

Section 1.2.1: 'Take account of any disabilities, including visual impairment, when planning and delivering care for adults with type 1 diabetes.'

Section 1.10.1: 'Assess awareness of hypoglycaemia in adults with type 1 diabetes at each annual review.'

Section 1.10.2: 'Use the Gold score or Clarke score to quantify awareness of hypoglycaemia in adults with type 1 diabetes, checking that the questionnaire items have been answered correctly.'

Section 1.10.3: 'Explain to adults with type 1 diabetes that impaired awareness of the symptoms of plasma glucose levels below 3 mmol/litre is associated with a significantly increased risk of severe hypoglycaemia.'

Section 1.10.4: 'Ensure that adults with type 1 diabetes with impaired awareness of hypoglycaemia have had structured education in flexible insulin therapy using basal–bolus regimens and are following its principles correctly.'

Section 1.10.5: ‘Offer additional education focusing on avoiding and treating hypoglycaemia to adults with type 1 diabetes who continue to have impaired awareness of hypoglycaemia after structured education in flexible insulin therapy.’

Section 1.10.6: ‘Avoid relaxing individualised blood glucose targets as a treatment for adults with type 1 diabetes with impaired awareness of hypoglycaemia.’

Section 1.10.7: ‘If target blood glucose levels preferred by adults with type 1 diabetes who have impaired awareness of hypoglycaemia are lower than recommended, reinforce the recommended targets.’

Section 1.10.8: ‘Review insulin regimens and doses and prioritise strategies to avoid hypoglycaemia in adults with type 1 diabetes with impaired awareness of hypoglycaemia, including:

- reinforcing the principles of structured education
- offering continuous subcutaneous insulin infusion (CSII or insulin pump) therapy
- offering real-time continuous glucose monitoring.’

Section 1.10.9: ‘If impaired awareness of hypoglycaemia is associated with recurrent severe hypoglycaemia in an adult with type 1 diabetes despite these interventions, consider referring the person to a specialist centre.’

Sections 1.12.1 and 1.12.2: ‘be alert to the possibility of the development of other autoimmune disease in adults with type 1 diabetes’ including Addison's disease and refers to guidance and advice in relation to testing for coeliac disease and monitoring for thyroid disease.