

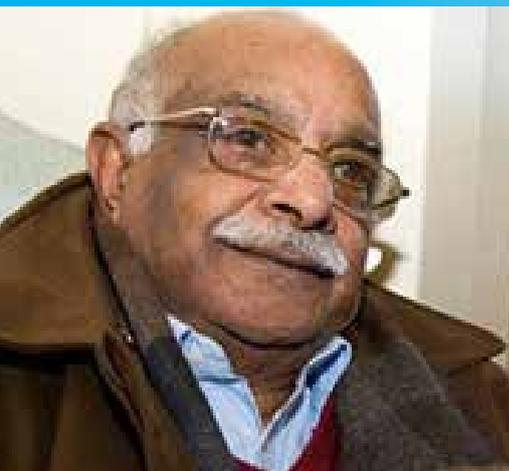
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End of Life Diabetes Care: Full Strategy Document

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Endorsed By:



End of Life Diabetes Care Strategy

Promoting appropriate and sensitive high quality diabetes care for all adults at the end of life

"You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."

*Dame Cicely Saunders
Pioneer in Hospice Care*

"It's only when we truly know and understand that we have a limited time on earth - And that we have no way of knowing when our time is up, we will then begin to live each day to the fullest, as if it was the only one we had"

*Elisabeth Kubler-Ross
American Psychologist*

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Foreword

End of life care involves providing support to allow people to die with dignity, keeping them as comfortable as possible until the end, and assisting families to manage this often distressing experience. In view of its high prevalence and associated complications and co-morbidities, diabetes is often present in those patients at the end of life.

On behalf of Diabetes UK, we are pleased to provide an up to date strategy on promoting high quality diabetes care at the end of life. This has long been overdue since it has been recognised that there are inconsistencies in standards applied, variation in care planning, and a lack of knowledge and clinical skills among both health and social care professionals in some of the important areas of end of life care.

This guidance should be seen to build on the strategic document called **End of Life Strategy** published by the Department of Health in July 2008* but focuses on the special issues and challenges provoked by end of life care for patients with diabetes. We hope that this new diabetes-related guidance will contribute to the development of consistent approaches in the delivery of this care at the end of life.

It should be seen as a platform for further partnership working with the third sector and the public.

Professor Alan Sinclair

Dr Jean MacLeod

July 2012

**End of Life Care Strategy - promoting high quality care for all adults at the end of life. Department of Health, July 2008*

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Executive Summary

Patients with diabetes who are at the end of life have a unique set of care needs including those relating to health and social care. However, End of Life Diabetes Care has been recognised as an area lacking quality standards and guidance on best clinical practice and commissioning.

This document aims to describe a consistent high quality approach towards end of life diabetes care, inform the wider healthcare workforce about key issues, clarify roles and responsibilities of all those involved in the providing end of life diabetes care, highlight emerging new training and educational requirements in this area, and to foster partnerships in end of life diabetes care with established palliative care programmes. We have attempted to cover the major clinical problems that people with diabetes at the end of life experience and how these can be best managed.

This includes a review of the use of glucose-lowering therapies and what targets are appropriate to minimise hypoglycaemia and improve patient safety, whilst at the same time engaging with patients and their carers to agree management strategies. Limitations to this approach include the lack of this topic in existing national or international clinical guidelines, lack of current service models in England for managing diabetes at the end of life and the scarcity of clinical research in this area.

We hope that health and social care professionals will respond positively to this guidance and that their approach to management will be more informed, and that future Commissioning Groups may want to adopt several key outcomes that can be used as a measure of effective diabetes care at the end of life.

Introduction and Drivers for Action

An area of diabetes care that has been recognised as lacking quality standards and has become increasingly topical is that of end of life diabetes care. Death in people with diabetes, as in many other chronic diseases, often follows a period of sustained ill health although acute vascular causes such as stroke or myocardial infarction may be responsible. It has been estimated that up to 75,000 people with diabetes die each year in England and therefore the appropriate management of diabetes with agreed actions by individuals and their families is important.

Modern day developments in end of life care within the NHS have centred around strategies such as the Liverpool Care Pathway (LCP) for the dying patient which was based on high quality integrated care at the bedside of the dying in the last few hours or days of life; this was an important feature of the national strategy published in 2008 [1]. However, recent concerns focussing on the public perception of the LCP, problems of communication between clinicians and carers or relatives, and adverse media coverage, has led to a national report chaired by Baroness Neuberger [2]. This includes withdrawal of the LCP and the development of new individualised, condition specific recommendations for end of life care.

Clinical guidelines for diabetes generally fail to include end of life care and research on best clinical practice in this area is scarce. Commissioning of this care is often not structured and organised within local care planning.

Maintaining appropriate metabolic control at all terminal stages of life might seem an achievable goal in most patients with diabetes but the influences of the stress response to severe illness, disturbances in glucose metabolism caused by malignancy, use of steroids, and frequent infections can be challenging for those healthcare clinicians tasked with providing this care [3]. Patients dying with diabetes may have an increased frequency of symptoms such as pain, constipation and fatigue, which can be difficult to ameliorate unless there is experience in providing tailored glucose-lowering therapy in combination with adequate pain relief including use of opiates. Regrettably, few specialists in diabetes care have received training in end of life care and as a consequence have had little input into managing patients in this scenario. In fact, lack of workforce knowledge and training in end of life care is a striking feature of those delivering diabetes care both in the hospital and in the community.

As a consequence of this background and as we enter a new commissioning phase for health in the NHS, it will be important that investments in end of life diabetes care are built around individualised care planning, design, training and education of the healthcare workforce, and defining quality standards of care for the purposes of assessment by regulatory bodies, HealthWatch, Local Health and Wellbeing Boards, clinical commissioning groups, the National Commissioning Board, and clinical audit. Where possible, these changes should align with other new developments in end of life care. It is important to note that general practitioners have an important role in promoting best clinical practice in this area [4].

Recognising the concept of a 'good death' for all people entering an end of life phase is important but can be an awkward aspect of caring to communicate although the key attributes of this which should be centred around freedom from pain, being with family and loved ones, and being treated with dignity and respect at all times, is paramount. This document aims to provide best clinical practice guidance in many of these areas, but other more specialist 'palliative' issues such as complex symptom control or pain management are covered elsewhere in other available literature.

Working Definition of End of Life Care

End of Life Care is care that:

“Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.”

(Source: National Council for Palliative Care 2006)

Purposes of this Guidance

This guidance document is primarily aimed at all those within the health and social care workforce who liaise, interact, or have management responsibilities for those patients (and their families/carers) with diabetes at their end of life. Below we define the key purposes of our full guidance document.

The key purpose of our full guidance document is to:

- Describe a consistent high quality approach towards end of life diabetes care provided by a series of quality standards
- Inform the wider healthcare workforce about the key issues in end of life diabetes care that provides a platform for sensitive, appropriate, and supportive care
- Provide clarification of the main roles and responsibilities of healthcare workers, carers, and patients themselves in end of life diabetes care
- Highlight the awareness of newly - identified training and educational needs for high quality end of life diabetes care
- To foster partnerships in end of life diabetes care with established palliative care planning such as the 'Amber Care Bundle' [6] developed by Guys and St Thomas' Foundation NHS Trust

Review of the Published Literature

There is little published evidence to demonstrate a preferred or effective approach to diabetes care at the end of life with no intervention studies reported. There are no studies which support or provide insight into glucose regulation, diabetes self-management, or use of particular glucose-lowering therapies.

In **appendix 1**, we also provide details of several key source documents and the few original papers that have a bearing on end of life care in diabetes. In addition we provide web addresses of sites that can provide additional information for healthcare and social care professionals.

Summary of Key Supporting Regulatory Statements

End of life care has created a need for health and social care professionals to have clear legal guidance on managing patients at this often difficult stage. This allows for patients to express their wishes before they might lose capability to do so and ensures that both family and other carers have a clear understanding of what has been officially recorded.

Each patient should have a care plan which should be reviewed regularly by the multidisciplinary team, the patient and carers as and when a person's condition, or wishes, change. This care plan should be made available to all who have a legitimate reason to access it [1].

Guidance in the areas of **Advance Decision to Refuse Treatment, Lasting Power of Attorney, and Advance Care Planning** has been provided in **Appendix 2**.

Defining Main Principles of Diabetes Care at the End of Life

A set of key principles underlie high quality diabetes care at the end of life and these have been summarised below:

- Provision of a painless and symptom-free death
- Tailor glucose-lowering therapy and minimise diabetes-related adverse treatment effects
- Avoid metabolic de-compensation and diabetes-related emergencies:
 - * frequent and unnecessary hypoglycaemia
 - * diabetic ketoacidosis
 - * hyperosmolar hyperglycaemic state
 - * persistent symptomatic hyperglycaemia
- Avoidance of foot complications in frail, bed-bound patients with diabetes
- Avoidance of symptomatic clinical dehydration
- Provision of an appropriate level of intervention according to stage of illness, symptom profile, and respect for dignity
- Supporting and maintaining the empowerment of the individual patient (in their diabetes self-management) and carers to the last possible stage

It is recognised that these may well be seen as ideal and often unattainable but all involved health and social care professionals should provide end of life diabetes care with these principles first and foremost in mind.

Key Features of an End of Life Diabetes Care Management

We have summarised a series of key features that should have an important place in the operation of an individualised end of life diabetes care plan.

1. Entry to the End of Life Plan

Formal entry to an individualised end of life care plan is usually when the health professional determines a stage is reached in a patient's illness that requires palliative care and is accompanied by a more detailed assessment of clinical and psychological need of the patient, and a focus on family / carer needs as well. It is often not possible to plan the likely immediate outcomes of a person with diabetes who is in the end of life phase. In those with diabetes, unless cancer supervenes, the onset of this palliative phase may occur after a period of chronic illness or if a severe vascular episode occurs such a disabling stroke or myocardial infarction. Entry to a care home because of sustained ill health or a recent admission into hospital can also sometimes be the beginning of a palliative phase. **Patients in an end of life care scenario require high quality care at every time point and every setting.** Key areas are noted below:

2. Role of Primary Care

The primary care team led by the GP has a vital role in the management of a patient entering a palliative care phase. Palliative care within a primary care setting can be enhanced through application of the QOF (Quality Outcomes Framework) that promotes each practice to have a palliative / supportive care register and hold a planning meeting to discuss patients during their end of life phase, which should include the patient, carers or family. If a patient lacks mental capacity and there is no appropriate family representative a patient advocate should be appointed. A series of competencies are needed to ensure that this care is of high quality and appropriate.

Some of the key areas, which involve the primary care team, are included below:

- Supporting the patient and family - beginning at the time of diagnosis of a condition likely to lead to palliative care or entry to end of life planning
- Liaison with palliative care team and with the community diabetes team
- To facilitate close working with other hospital and community-based specialists as part of a multidisciplinary approach to end of life diabetes care
- Referral to specialist care for assistance with complex treatment decisions such as frequent hypoglycaemia, use of insulin, or managing steroids
- Management of pain
- Withdrawal of treatment
- Referral to hospice care

Working across boundaries of health and social care is needed and focused care around the patient and family is paramount.

3. Role of Community Diabetes Team

The community diabetes care team may change some of its key relationships and method of working when new commissioning groups are established although their major roles will be the same. The team provides specialist diabetes care local to the patient and primary care. It is a valuable source of support and advice to patients and their families, and can offer effective liaison with hospital-based specialist care. Key roles and responsibilities have been included below:

- Providing advice and support on glucose targets (high and low), meal planning, glucose monitoring and insulin therapy to patients and families
- Awareness of the increased risk of further weight loss during the end of life phase due to cancer-related cachexia, Metformin and GLP-1 receptor agonist-associated gastrointestinal effects such as nausea, and reduced food intake: liaison with a community-based palliative care physician and/or dietitian
- Recommending treatment changes including alteration in insulin dose and regimen to the primary care team
- Management of hypoglycaemia
- Managing glucose fluctuations during steroid therapy
- Liaison with hospital-based specialist care and the primary care team and family when withdrawal of treatment is being considered
- Ongoing liaison with, and feedback from, patient/carers/family and engagement in their own, their loved ones, death

4. Referral to Specialist Care

In the context of this guidance, this section predominantly deals with referral to a local diabetologist or diabetes healthcare team which may be community-based. Referral to other specialist areas such as nephrology, ophthalmology or vascular surgery will be according to the situation.

There are six key referral situations:

1. Failure to control distressing symptoms of hyperglycaemia
2. Where further management requires complex treatment decision-making, e.g. commencing steroids, changing an insulin regime
3. In the presence of marked dehydration or infection failing to respond to treatment
4. When diabetes-related emergencies supervene such as hyperosmolar hyperglycaemia state
5. When withdrawal of glucose-lowering therapies including insulin are being considered
6. In the face of marked patient or carer anxiety

5. Hospice Care

'Refer to hospice when goals are focused on quality of life rather than intervention'

Hospice care offers a range of services to patients during the palliative phase and at the end of life including outpatient and inpatient care, day therapy services, and family support services.

Few hospices are likely to have staff trained in providing quality diabetes care but this will have less relevance for patients admitted into this setting at an advanced stage of their illness.

Common referral criteria include:

- Where complex palliative issues exist such as difficult pain
- For end of life care during last few days of life
- Where psychological or social issues exist and hospital care is considered to be inappropriate or where no nursing home is available (maximum stay 2 weeks in some hospices)

Where good communication channels exist between health and social services, an 'in reach' contribution can still continue from community-based dietitians, diabetes specialist nurses, GPs and hospital specialists. The availability of a palliative care physician who often has a contractual arrangement with the hospice ensures that major clinical needs, such treatment of acute illness or alleviation of intractable pain due to malignant infiltration, can be managed effectively.

Management Goals in Key Clinical Areas

1. Glucose control targets

No published evidence exists to justify any particular glucose or HbA1c range to aim for in end of life diabetes care management. It is likely that the optimal range will vary according to the stage of illness, ability of the patient to eat and drink normally, the presence of hypoglycaemia, the nutritional status, and the treatment given.

Many patients will not want to have blood glucose estimations done regularly and the utility of this test in an end of life care scenario is questionable.

Each patient with capacity should be asked about what they want done.

Based on wide discussion with experts in the field, community-based nurses and physicians, and the available literature, we have decided to recommend the following glucose control target ranges:

- Aim 1:- no pre-meal glucose level **less** than 6 mmol/L
- Aim 2 :- no pre-meal glucose level **higher** than 15 mmol/L

These are easy to remember, practicable, and are likely to minimise the risk of hypoglycaemia, and lessen the development of a metabolic decompensation such as hyperosmolar hyperglycaemic state or diabetic ketoacidosis (DKA).

Where possible, patients must be given sufficient support to maintain a lower level of glucose than **15 mmol/l** as levels above this can be associated with symptoms of hyperglycaemia.

Asking for a fasting glucose level in an end of life care situation should be avoided.

It should be remembered that many patients with existing diabetes will be aware of targets for control that they have been previously working towards and will need an explanation and reassurance to agree a new set of glycaemic targets. This must be a basis for discussion between the health professional and the patient and family with the aim of an agreement be reached.

An additional set of pre-meal glucose values may be helpful where glucose monitoring is still considered worthwhile:

- Between **6 - 9 mmols/L** is acceptable if symptom free

This range may be adjusted upwards if :

- (a) Patients have hypoglycaemia before meals despite mid meal snacks
- (b) Long gaps occur between meals because of poor appetite and intake

2. Tailoring medication including glucose-lowering therapies

We have adopted **four (4) stages (A - D)** within the end of life scenario these are colour coded in line with other nationally recognised stages of end of life care:

A - Blue "All" from diagnosis stable with year plus prognosis

B - Green "Benefits" DS1500 Unstable / Advanced Disease Months prognosis

C - Yellow "Continuing Care" Deteriorating Weeks prognosis

D - Red "Days" Final days / Terminal Care Days prognosis

These provide opportunities to review management and consider the use of glucose-lowering therapies where appropriate and other relevant drug therapies. Some patients will not need additional drug therapy at this stage.

In **appendix 3**, we have examined in more detail how both oral agents and insulin therapies can be adapted to minimise symptoms of hyperglycaemia, avoid hypoglycaemia and maximise patient safety. This risk-benefit analysis is crucial in terminally ill patients. The stages of end of life diabetes care we have adopted are as follows:

A - Blue: "All"; recently diagnosed as in end of life care; stable with one year plus prognosis

Cardio-protective therapies (ACE inhibitors, angiotensin receptor blockers, aspirin, statins) should be reconsidered in the light of the diagnosis. ACE inhibitors (e.g. ramipril or lisinopril) or angiotensin receptor blockers (e.g. losartan, candesartan) may be useful in managing cardiac failure or hypertension, so withdrawal may not be ideal but dose reductions may need to be considered. Patients may experience more gastrointestinal effects from aspirin with poor dietary intake or concurrent steroid use. People on aspirin and steroids should be considered for gastrointestinal haemorrhage protection with a proton pump inhibitor or suitable alternative. Cholesterol management may no longer be a priority and the risk of side effects from statins will rise if renal or liver functions are affected by disease progression. Glucose-lowering therapies should be reviewed and the targets for glucose control agreed. Weight loss may mean a reduced need for glucose-lowering or offer potential for simplifying regimens including insulin.

B - Green: Receiving benefits as terminally ill; unstable or advanced disease; one to two months prognosis

At this stage the aim is to keep drug interventions to the minimum that will control symptoms. All of the comments for **stage A** apply but complex regimens should be reviewed especially where patients are on combinations of oral hypoglycaemic agents with insulin. It is generally simpler for patients to switch from combinations to insulin alone, once or twice daily insulin.

- Insulin alone is a simpler option than combinations of tablets and insulin

Insulin regimens should be simplified if possible. Every effort should be made to assist carers in administering the insulin if required and simplifying the regimen may be helpful in this respect.

If moving from twice daily to once daily insulin, the starting dose of long acting insulin such as Glargine or Insulin Degludec should be less than the total dose of twice daily isophane or pre-mixed insulin and 75% of total previous dose is recommended

- Once daily insulin is a simpler option if carers are involved and/or appetite is changing

C - Yellow: "Continuing Care" With Patient Deteriorating and up to One to Two Weeks Prognosis

Patients may present to the diabetes healthcare professional at this stage, in which case all of the suggested changes in stages **A** and **B** should be considered. Please keep in mind that there may be little time to establish a new insulin regimen. Intensive support can be needed for dose adjustments as well-being, activity and appetite can change day to day. Managing diabetes can be an added stress at an emotional time for patients and carers. Relaxing targets for control may seem like "giving up" for some while others may view managing diabetes in addition to their terminal illness as "pointless".

3. Patients with problems swallowing or poor appetite

Changes in meal size or frequency can have a significant impact on glucose concentration. Patients with diabetes may be taking multiple tablets, which can be difficult to swallow due to size or number, requiring a review of tablet doses and frequency. Metformin, in particular, can cause gastrointestinal symptoms and worsen appetite in vulnerable patients.

Insulin-treated patients will need a review of doses and possibly regimen if timing and size of meals change. Avoidance of dietary sugars may no longer be possible or appropriate as food choices become limited and therapy may have to be adjusted around the altered dietary choices.

Dietetic input is useful in reinforcing food choices appropriate to the patient's overall condition rather than food choices purely relevant to their diabetes.

Calorie-dense foods (including chocolate) are encouraged despite their adverse impact on glucose concentration.

Adjusting medication is preferable to limiting the diet but therapy will have to match small frequent meals.

- Avoid long-acting sulphonylurea preparations (Glibenclamide, Glimepiride) if small meals are being taken
- Repaglinide or Nateglinide can be useful for patients managing small regular meals with dose adjusted according to intake
- Low dose insulin may be the only option for patients whose glucose levels are high despite a significantly reduced oral intake
- Patients on insulin with poor intake will need lower doses
- Strict avoidance of added sugars is often impractical when food choices are already limited
- Patients may request 'sugary' nutrients which should be provided and / or agreed without the need for undue reluctance by staff. This may require further 'tailoring' of the medications being used

D - Red: in the final days of life / terminal care with one or more days prognosis

Ideally by this stage diabetes treatment has been minimised so that few changes are needed in the last days of life. If the stage is reached where the patient is bed bound, semi-comatose, no longer able to take tablets, no longer able to eat and only able to take sips of fluid, use of local protocol, or an alternative guidance such as "Deciding Right" should be considered.

At this stage, the **Flowchart for Diabetes at End of Life (appendix 4)** describes how to manage diabetes in the dying patient. It can be reassuring for relatives and carers to know that this additional plan of care is being followed and that the diabetes is being managed differently rather than being "ignored".

The flowchart has been devised to minimise symptoms of diabetes but keep invasive testing to the minimum needed to achieve that aim.

4. Managing the effects of steroid therapy

Steroid therapy is frequently used in palliative care for symptom control, usually as dexamethasone or prednisolone. Regardless of the indication, the impact of steroids on glucose control can cause additional hyperglycaemic symptoms. Once daily steroid therapy taken in the morning tends to cause a late afternoon or early evening rise in glucose levels which can be managed by a morning sulphonylurea (e.g. Gliclazide) or morning isophane insulin (e.g. Insulatard, Humulin I or Insuman Basal).

A flowchart for managing diabetes at the end of life is provided in **appendix 4**, and a separate flowchart for use of once daily steroid therapy has been provided in **appendix 5**.

If steroids are to be given twice daily, for example splitting higher doses of dexamethasone, it will be necessary to recommend an alternative approach to setting times for testing glucose levels and for managing the impact on blood glucose. Twice daily Gliclazide or isophane insulin can be effective but there is a risk of early morning hypoglycaemia and care must be taken in adjusting doses with that risk in mind.

If hypoglycaemia is a concern, once daily insulin Glargine given in the morning may be a safer, less complex regimen, especially for those new to insulin. Early discussions with the diabetes specialist team can assist in choosing the more appropriate steroid and hypoglycaemic treatment regimens.

Short-term courses (<3 days) of steroids may only require closer monitoring but longer courses will require a review of glucose-lowering therapy and may result in a switch from oral agents to insulin. In this latter situation, an isophane insulin (e.g. Humulin I) can be given once daily. Liaison with a community dietitian may assist in meal planning. Longer-term influences on the hypothalamo-pituitary axis should not be major concern if steroids are instituted late in the end of life phase where death is imminent.

5. Hypoglycaemia Management

Hypoglycaemia can be troublesome and distressing at any time in people with diabetes on glucose-lowering therapies but at the end of life, every effort should be made to avoid this side-effect of treatment. The following help to reduce hypoglycaemia:

- Agree a care plan and glucose targets
- Be cautious when anorexia develops
- Maintain at HbA1c at no lower than 59 mmol/mol (7.5%) depending on the individual's life expectancy as HbA1c will be less relevant in patients with months or days left to live
- Tailor insulin therapy and reduce insulin dose errors

Other factors / steps that should be considered are:

- Rationalisation of glucose-lowering treatment for diabetes
- Involve an experienced community dietitian
- Early identification of risk factors for hypoglycaemia
- Treat pain effectively
- Assess impact of weight loss
- Assess influence of nutritional deficits
- Assess influence of opiates/other pain killers on appetite

a. Identifying those at risk:

These include all insulin, sulphonylurea (e.g. Gliclazide, Glipizide) and prandial regulator users (e.g. Nataglinide, Repaglinide). Patients who are at particular high risk include those who also have one or more of the following:

- Poor appetite / erratic eating pattern
- Weight loss
- Renal deterioration
- Liver impairment / carcinoma

b. Identifying hypoglycaemia: signs and symptoms

The patient may feel one or more of the following symptoms listed below:

- Sudden onset of hunger
- Sweating
- Palpitations / feeling anxious
- Feeling "jittery"
- Tingling in lips
- Feel dizzy or faint
- Feel confused or find it difficult to concentrate

Other noticeable symptoms

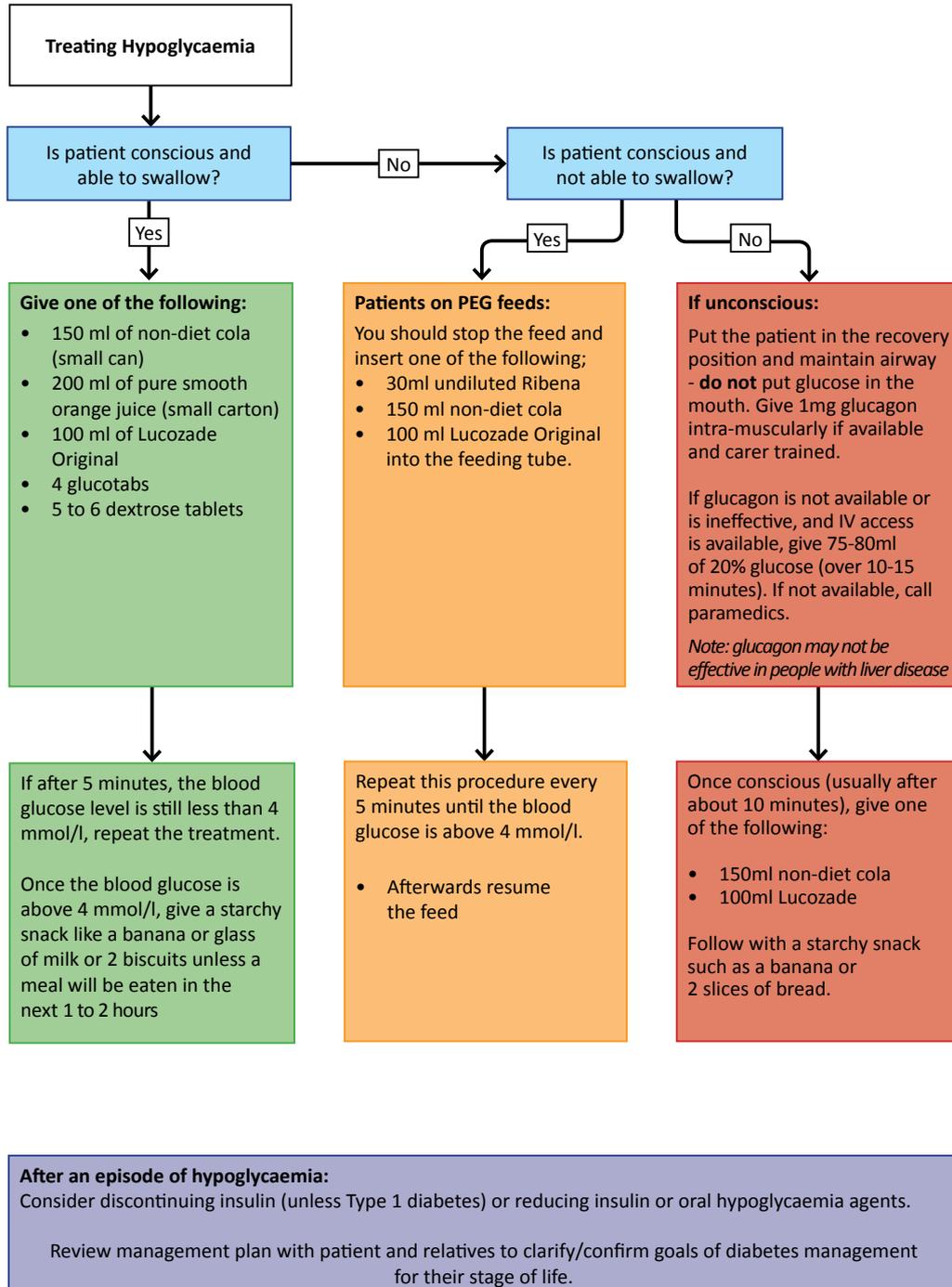
- They may look pale, become confused, have behaviour change, become very drowsy, and lose consciousness
- Sweating, fits, and skin colour change in a drowsy or unconscious person may be due to hypoglycaemia
- Do not assume if the patient is comatose that it is due to the end of life primary condition
- Remember than many older people with diabetes may not display or experience the symptoms / signs of hypoglycaemia.
- Where there is doubt, blood glucose estimation will be required

c. Treating hypoglycaemia

This has been provided as a flowchart in the body of this guidance (see below):

Fig 1

End of Life Diabetes Management - Treating Hypoglycaemia



Version 2 5th July 2012

d. Sick-Day Management

A number of common precautions are often needed to minimise the development of a number of frequently occurring acute metabolic complications during the end of life phase, and these are indicated below in table 1 below:

Table 1: Type 2 Diabetes: Specific Advice

Type 2 on diet alone or tablets that are not sulphonylurea or prandial regulators	Type 2 diabetes on a sulphonylurea, prandial regulator and/or insulin or GLP1 Agonist
Sip sugar-free fluids regularly (aim for 100 ml per hour)	Check blood glucose only to confirm symptoms of hyperglycaemia or hypoglycaemia
Offer frequent small portions of easily digested foods or fluids e.g. soup, ice cream, milky drinks	Offer frequent small easily digested carbohydrate foods to replace meals if unable to eat normally. Offer sips of sugar-free fluids, aiming for 100 mls over an hour
Observe for signs and symptoms of hyperglycaemia and dehydration	
Only check capillary blood glucose to confirm hyperglycaemia: aim to maintain blood glucose at 15 mmol/l or less	Consider increasing (if blood glucose levels above 15 mmol/l) or reducing (if blood glucose levels less than 6 mmol/l) the sulphonylurea or insulin dose
Consider stopping Metformin if the patient has sickness / diarrhoea	Glycaemic treatments may be discontinued if the patient is not eating and blood glucose level is less than 15mmol/l and patient is symptom-free

Table 2: Type 1 Diabetes: Specific Advice

Type 1 on insulin treatment - do not discontinue the long-acting insulin
Sip sugar-free fluids regularly (aim for 100 ml per hour)
If unable to eat usual meals, offer frequent small portions of easily digested foods or fluids e.g. soup, ice cream, milky drinks
Test for urine or blood ketones if patient has symptoms of hyperglycaemia and dehydration. If positive, test blood glucose and ketones every 2 hours. Continue usual insulin regime (e.g. isophane insulin daily e.g. Humulin I, Insulatard or Insuman Basal but give an additional 10% of current total average daily insulin dose as short-acting insulin (e.g. Humulin S, NovoRapid, Apidra,) every 2 hours if ++ or greater on urine ketone strip or greater than 1.5 mmol on blood ketone test
If ketone levels do not improve, and the patient is vomiting, admit to hospital for intravenous insulin and rehydration see (please see sick day rules)

e. Withdrawal of treatment

Withdrawal of part or whole of diabetes-related treatment can be considered under 6 conditions listed below:

- When the patient with diabetes is entering the terminal phase of life
- Where frequent treatment-related hypoglycaemia is causing distress and significant management difficulties
- Where continued treatment with insulin poses an unacceptable risk of hypoglycaemia or where the benefits of stricter glucose control cannot be justified
- Where continued use of blood pressure or lipid lowering therapy cannot be justified on health benefit considerations
- Where continued food or fluids is not the choice of the patient
- Where prescribing anti-infective therapy is not likely to benefit the patient

Multiple factors may influence this process:

- Patient's wishes
- Dealing with concerns by family of a 'euthanasia' approach
- Presence of an Advance Directive
- Intravenous / subcutaneous fluid or nasogastric feeding may be warranted for a brief spell

Close liaison with the patient, family and GP is warranted in this scenario.

Training and Education of the Workforce

1. Competencies for End of Life Diabetes Care

Competency is defined as:

“the state of having the knowledge, judgement, skills, energy, experience and motivation required to respond adequately to the demands of one’s professional responsibilities” [5].

The care of people with diabetes at the end of life will be given by a wide range of disciplines, with a range of experience and qualifications. Traditionally, most care has been given by nurses and medical staff, but with changes in healthcare workforce, care will also be given by unregistered practitioners or healthcare professionals with experience of end of life care or diabetes care but usually not both.

The competency framework listed in **appendix 6** is adapted from the comprehensive ‘**Integrated Career and Competency Framework for Diabetes Nursing**’ (TREND UK 2011). It illustrates the different competencies expected from healthcare professionals and unregistered practitioners involved in the care of someone with diabetes at the end of their life.

This is useful for commissioners to ensure the correct level of staff is available for the service required. It also acts as a basis on which to guide nurses to develop their career in this speciality.

A recent ‘**Rapid Response Report**’ from the National Patient Safety Agency (NPSA) summarises guidance aimed at decreasing the number of incidents involving insulin (visit www.nrls.npsa.nhs.uk/alerts).

NHS Diabetes has also produced a resource that has been designed for all health professionals who need to administer insulin for patients with diabetes which is available at: <http://www.healthcareea.co.uk/nhsdiabetes>

2. Insulin Pump Training

Insulin pumps are increasing being used to manage diabetes in an end of life phase. Patients are likely to be well informed about adapting their pump settings for illness and have a good awareness of food intake in terms of carbohydrate and protein content.

Adjusting pump settings to cope with treatments such as chemotherapy, radiotherapy or to cope with lifestyle and appetite changes will need support from members of the specialist team who are trained in managing pumps. Insulin sensitivity will change in response to disease progression, which will impact on pump settings, particularly for those who rely on pumps’ more complex capabilities. As long as the patient feels capable of using the pump, they should be encouraged to do so. Carers may need education in pump adjustment if it is physically difficult to make setting changes and may be involved in cannula changes.

As with those on standard injectable insulin regimens though, predictable changes in treatment can be managed still using the pump allowing patients continuing autonomy. Background insulin rates can be adapted to cope with steroid usage for example, while bolus settings can be altered to cope with sip feeds or other supplements.

At the stage where bolus doses are not being used or if patient and carers are experiencing difficulties with the practical aspects of using the pump, patients can revert to subcutaneous injections using once daily isophane or analogue insulin. The dose of subcutaneous insulin is likely to be higher than the total daily pump delivered insulin dose.

Should patients wish to remain on their pump, the settings can be adapted to cope with even the last days of life. In that situation close co-operation among professional teams is crucial since the equipment may be unfamiliar to the caring team. The specialist diabetes team can advise on transfers at any stage but planning ahead will minimise anxiety on all sides.

On a practical note, carers do need to remember that the pump may be returned to the diabetes team after death as re-conditioning may be possible allowing further use.

3. Carers' perspective

Good communication is essential in order for patients and their families to understand the change in emphasis of care and to formulate a plan together on how to manage their diabetes. Contact with the diabetes team may become less with the patient directly but more with carers, "about" rather than "with" and it is worthwhile being open about that initially so concerns regarding confidentiality are explored.

In addition to coping with a progressive illness, carers may have to take on tasks related to diabetes such as monitoring or insulin injections. Giving up those tasks may be difficult for the patient as it represents a further loss of influence over an important aspect of their life. Similarly erratic glucose levels can be stressful for patients and carers, particularly if the carer is new to insulin changes and trying to cope with a changing diet and appetite. Managing a complex regimen of tablets can be confusing and simplification can be helpful to carers as well as the patient.

Depression is common in diabetes and in palliative care and so is not an unexpected issue for patients in the last stages of life. Of course that impacts on family and carers who may themselves be experiencing similar symptoms of loss, powerlessness and resentment.

A new diagnosis of diabetes may be viewed as additional "bad news" by patients and carers and anxieties around the diagnosis will need to be addressed. Education strategies dealing with diet, oral therapies or insulin need to be adapted and highly individualised. Including family and carers at an early stage can reduce anxieties later if responsibility for testing or injecting shifts from patient to carer.

4. National Bereavement Survey (VOICES)

The National Bereavement Survey aims to capture the Views Of Informal Carers and an valuation of Services (VOICES). It is a postal questionnaire to measure satisfaction with services received in the year before death. To avoid burdening the patients further this survey collects information from bereaved relatives and friends in the months after the patient's death. Data from 2011 should soon be available to improve services and care for people and their families at the end of life.

The Office for National Statistics (ONS) is carrying out the survey on behalf of the Department of Health. More information is available at: <http://www.ons.gov.uk/ons/about-ons/surveys/a-z-of-surveys/national-bereavement-survey--voices-/index.html>

Quality Care Standards

Generic quality care standards were published by the Department of Health in their document called 'End of Life Care Strategy - promoting high quality care for all adults at the end of life' in 2008 [1].

NICE have issued some guidance in this area relating to end of life care with the following statements / standards being directly relevant to those with diabetes:

- People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences
- Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers

More information can be found in full at: <http://www.nice.org.uk/media/EE7/57/EoLCFinalQS.pdf>

1. Key measures that are of value and required in end of life diabetes care

End of life is a complex period of health care and the outcomes related to diabetes management will vary significantly between individuals and at different phases in person's progression to death. The end-of-life trajectory is also variant while some patients will experience a rapid curvilinear decline others may experience a more gradual decline with intermittent periods of improved health. There is further variation in relation to the place of care, between care at home, care in hospital, care in hospice or residential care.

Many factors associated with end-of-life care may precipitate hyperglycaemia (steroids, concurrent infection, tumour specific effects, and the stress response) and/or hypoglycaemia (loss of appetite, weight loss and renal or hepatic failure). Nevertheless, there are important areas that can be addressed in improving diabetes care at the end of life; in some circumstances, these may be seen as outcomes of care. These outcomes are focussed on symptom reduction, patient safety, patient choice and quality of life. These outcomes might be categorised in relation to different management conditions (as these are not all mutually exclusive).

We have identified 3 specific categories in relation to this perspective and have aligned them with the 4 stages of end of life care defined above - see table 3:

Table 3: Key Measures

Condition 1 (aligned with stage A - recently diagnosed as in end of life care; stable with 1 year plus prognosis)	Condition 2 (aligned with the stage B receiving benefits as terminally ill; unstable or advanced disease; one to two months prognosis, and stage C - : "Continuing Care" with patient deteriorating and up to one to two weeks prognosis)	Condition 3 (aligned with stage D - in the final days of life / terminal care with one or more days prognosis)
<p>Diabetes is recognised and addressed in overall care management plan for end-of-life care.</p> <p>Patients with diabetes and their carers are supported in maintaining self-management of their diabetes as far as possible in respect of their choice and capacity to do so.</p> <p>Patients and carers should receive a good explanation of how their illness may affect their diabetes and what to do if a problem should occur.</p> <p>Patients' diabetes care providers are consulted and involved in end of life care planning.</p> <p>Medication is reviewed in relation to current meal planning, eating behaviour, and blood glucose estimates if measured.</p>	<p>Palliative treatment stage (some patients may have active treatments and or surgical interventions that could impact on glycaemic control)</p> <p>All patients receiving steroids should have their blood glucose levels monitored regularly and maintained in the non-fasting range of 6 - 9 mmols/L pre-meal as far as possible to avoid hyperglycaemic symptoms (insulin therapy should be used to minimise hyperglycaemic symptoms).</p> <p>The specialist diabetes team should be consulted prior to any invasive procedure when the patient is on insulin therapy or where there is significant risk of hypo or hyperglycaemia.</p> <p>Patients with parental feeding and or nasogastric feeding should be assessed to ensure that diabetes therapies are adjusted to reflect glucose loading of the feeding regimen, preventing hypo and hyperglycaemia.</p> <p>Palliative support stage. Patients are supported in maintaining their self care behaviours as far as they are able. Patients can still access diabetes supportive services as far as they are able (including eye screening, foot assessment and specialist diabetes services).</p> <p>Blood glucose levels are monitored in accord with the patient's diabetes treatment plan. Patients on multiple daily injections of insulin or pump therapy should be asked about having pre-meal and pre bedtime readings monitored.</p> <p>Non-fasting blood glucose levels should be maintained in the range of 6 -9mmols/L pre-meal as far as possible. Treatment regimes should be simplified to minimise patient and/or carer burden.</p> <p>Potentially distressing diabetes symptoms polyuria (continence); pain; thirst (mouth care) are assessed regularly.</p> <p>Pressure area risk assessment undertaken addressing underlying neurological and ischaemic risk with appropriate pressure reliving intervention.</p>	<p>During the last few days of life, poorly managed blood glucose can contribute significantly to a patient's end of life experience.</p> <p>Osmotic symptoms are assessed and monitored carefully.</p> <p>Patients blood glucose levels are checked regularly if there is evidence of elevated hyperglycaemia with symptoms or to exclude hypoglycaemia, otherwise testing should be kept to a minimum.</p> <p>Diabetes treatment is simplified to minimise patient distress while preventing unnecessary symptoms.</p> <p>Oral hypoglycaemic agents are stopped in patients with Type 2 diabetes and insulin therapy is simplified to minimise the number of injections the patient requires to prevent excess hyperglycaemia.</p> <p>Patient/s carers are asked their views / concerns and these are used to inform the dialogue and agree treatment plans.</p>

2. Major 'metrics' required to be collected/defined in end of life diabetes care

To assist community diabetes and palliative care teams to ensure that the services they are providing in end of life diabetes care are of high quality the following key metrics are advised:

- Number of patients with diabetes who die in place of choice
- Number of avoidable hospital admissions
- Number of avoidable ambulance call outs and emergency department attendances
- Number of severe hypoglycaemic events requiring third party treatment
- Number of pressure ulcers

3. Key audit measures

Audit measures are used to inform quality improvement, and feed into the commissioning of services at this important phase in the care of a patient with diabetes at the end of life.

Key audit measures should include:

- Documented diabetes assessment incorporated into their EOL care plan
- Documented patient/carer education on impact of illness progression on diabetes care (including self-management implications)
- Blood glucose levels monitored regularly during therapies likely to precipitate hyperglycaemia
- Osmotic symptoms assessed, recorded and treated
- Pressure area risk assessed, recorded and treated
- Patient/carer feedback about their patient reported outcomes, engagement in care, being listened to
- Recorded number of Insulin/medication errors
- Alignment of food intake with prescribed medication for glucose-lowering

Main Conclusions

This guidance has been developed as a template for a national End of Life Diabetes Care Strategy.

It emphasises the importance of:

- Early recognition of the influence of diabetes, a long term condition on mortality
- Ensuring that end of life care services map, align, integrate with existing health care planning in diabetes
- An agreed set of effective interventions / actions that aim to address key healthcare needs from clinical / administrative perspectives
- A commissioning framework for end of life care that meets both quality standards and aligns closely with diabetes care policies
- A series of specifications for end of life care in diabetes that are robust and appropriate to the wide nature of many patients in this situation
- Monitoring / feedback of key measures to inform ongoing quality improvement and service commissioning covering safety, clinical effectiveness and patient / carer involvement

Whilst we have many systems in place within our health and social care sectors to deliver high quality end of life diabetes care, we still lack an in depth appreciation of the complex medical, psychological, and emotional issues surrounding this scenario.

We have described some practical examples of this by providing a series of clinical cases which raise many of these issues (see **appendix 7**).

End of life diabetes care requires further research although developing a highly skilled workforce with new competencies will address part of this important need.

Appendices

Appendix 1: References and Resources

Numbered:

- [1] End of Life Care Strategy - promoting high quality care for all adults at the end of life. Department of Health, July 2008
- [2] Neuberger J (2014) More care, less pathway: A Review of The Liverpool Care Pathway https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf accessed 29/9/13
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- [4] Mitchell G (2003) How well do General practitioners deliver palliative care? A systematic review. Pall Med 16. 457-464
- [5] Roach MS (1992) The Human Act of Caring: A blueprint for the Health Professions. 2nd edn. Canadian Hospital Association Press, Ottawa
- [6] Guys and St Thomas' (2012) The Amber Care Bundle- A guide for patients, their relatives and carers www.ambercarebundle.org accessed 29.9/13

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Dunning T, Martin P, Savage S, Duggan N. Guidelines for managing diabetes at the end of life. Nurses Board of Victoria, Australia. 2011 (ISBN 978-0-646-53610-1)

McCoubrie R, Jeffrey D, Paton C, Dawes L. Managing diabetes mellitus in patients with advanced cancer: **a case note audit and guidelines**. Eur J Cancer Care (Engl). 2005 Jul;14(3):244-8

Murray, S and Sheikh, A (2008) Making a difference - Palliative care beyond cancer - Care for all at the end of life. BMJ 336(7650):958

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Quinn K, Hudson P, Dunning T. **Diabetes management in patients receiving palliative care**. J Pain Symptom Manage. 2006 Sep;32(3):275-86

Smyth T, Smyth D. **How to manage diabetes in advanced terminal illnesses**. Nurse Times. 2005 Apr 26-May 2;101(17):30-2

TREND-UK (2011) An Integrated Career and Competency Framework for Diabetes Nursing 3rd edn. SB Communications Group, London available on www.trend-uk.org

Vandenhoute V. Palliative care and type II diabetes: A need for new guidelines? [Am J Hosp Palliat Care](http://www.amj Hosp Palliat Care). 2010; Nov;27(7):444-5

Palliative and end of life care guidelines for cancer and non-cancer patients 3rd Edition 2012- NHS North of England Cancer Network

Useful Websites:

End of Life Care Strategy
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

Commissioning for Diabetes End of Life Care Services . February 2010. NHS Diabetes
http://www.diabetes.nhs.uk/commissioning_resource

Gold Standards Framework. Department of Health.
<http://www.goldstandardsframework.nhs.uk/>

Liverpool Care Pathway for the Dying Patient (LCP)
<http://www.mcpcil.org.uk/liverpool-care-pathway>

National Audit Office: End of Life Care publication 26 November 2008 http://www.nao.org.uk/publications/0708/end_of_life_care.aspx

Royal College of General Practitioners. November 2009.
http://www.rcgp.org.uk/college_locations/rcgp_scotland/initiatives/end_of_life_care.aspx

Scotland End of Life Care Strategy 2008.
www.palliativecarescotland.org.uk/publications/Palliative%20and%20End%20of%20Life%20Care%20in%20

Appendix 2: Key Supporting Regulatory Statements

These are summarised as follows:

Advance decision to refuse treatment (ADRT)

This is a verbal or written legally-binding refusal of specified future treatment by an adult aged 18 or over with capacity regarding their future care should they lose capacity for this decision. Although there is no requirement to involve any professional, advice from a clinician can help ensure the statement is clear, while legal advice can ensure a written document fulfils legal requirements. If the refusal involves the decision not to receive life-sustaining treatment, additional requirements are necessary including having a witness to the signing of the statement.

Because of the time needed to assess the validity and applicability of an ADRT, they are not helpful in acute emergencies that require immediate treatment, but must be acknowledged when time allows.

Lasting Power of Attorney (LPA)

There are two different types of LPA:

- A property and affairs LPA: this covers finances and replaces the previous Enduring Power of Attorney. It does not have power to make health decisions.
- A personal welfare LPA (also called a health & welfare LPA by the Office of the Public Guardian): this must be made while the individual has capacity, but only becomes active when the individual lacks capacity to make the required decision.

The LPA must act according to the principles of best interests and this can be extended to life-sustaining treatment decisions but this must be expressly contained in the original application. A personal welfare LPA only supersedes an ADRT if this LPA was appointed after the ADRT was made, and if the conditions of the LPA cover the same issues as in the ADRT

Advance Care Planning (ACP)

This is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future. If they wish, they can set on record choices or decisions about their care and treatment so that these can then be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to make decisions once their illness progresses. ACP has three possible outcomes:

- A verbal or written advance statement of wishes and feelings, beliefs and values
- A verbal or written advance decision to refuse treatment (ADRT) (must be written with specific requirements if refusing life-sustaining treatment)
- A lasting power of attorney

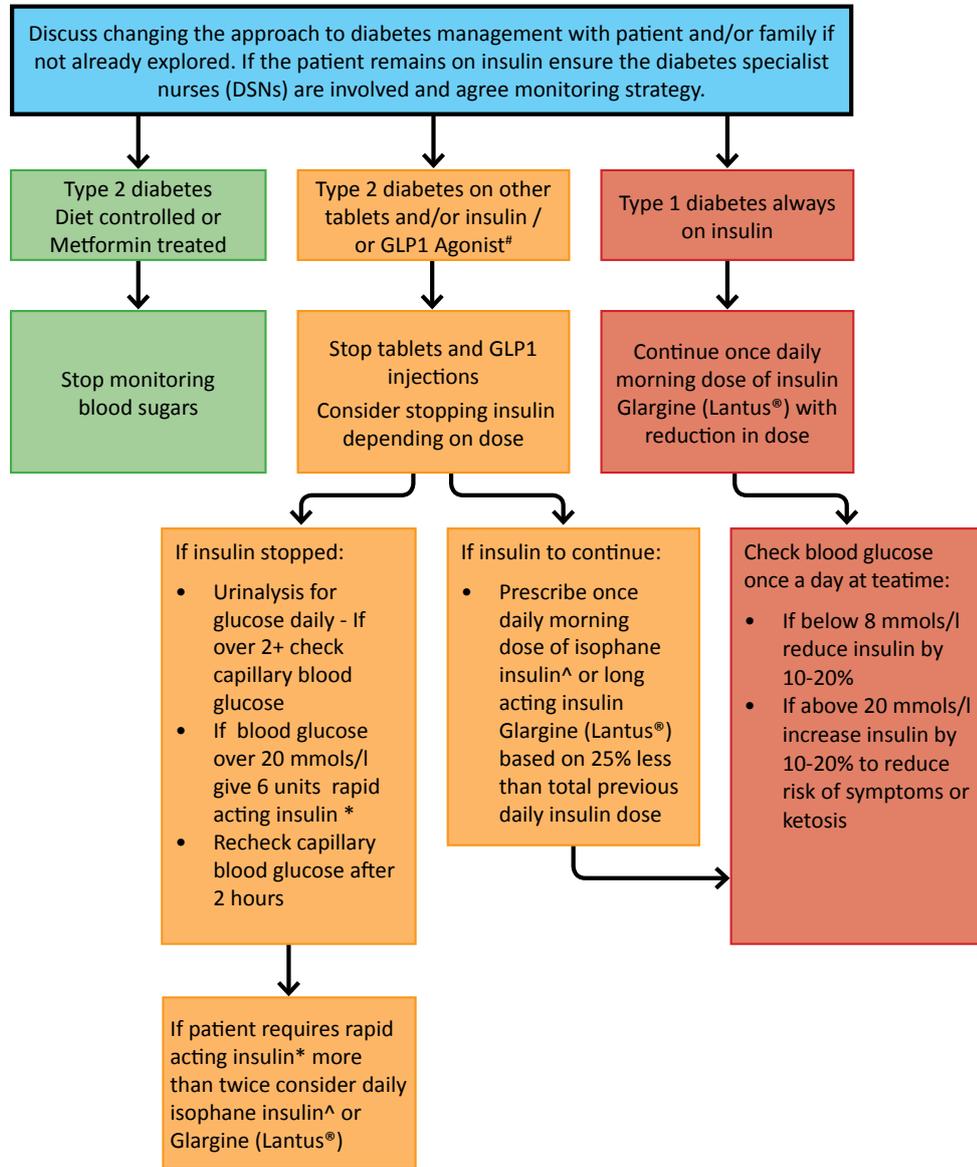
Appendix 3: Use of oral glucose-lowering therapies and insulin in end of life diabetes care Insulin (all types)

Metformin (standard Metformin or Glucophage SR®)	Sulphonylureas (gliclazide / glipizide / glimpiride)	Pioglitazone	Gliptins	GLP-1 analogues (exenatide or liraglutide, Lixisenatide and Bydureon)	Sodium Glucose Co- Transporter 2 Agents (SGLT2) Dapagliflozin (Forxiga)
Review dose according to changing renal function	Review if dietary intake is reduced and/ or there is significant weight loss	The risk- benefit ratio for pioglitazone in patients with terminal disease requires review and should be only prescribed if benefits can clearly be identified	Review doses in accordance with individual licences if renal function deteriorates	Review if eating patterns change or significant weight loss occurs	Starting dose is 10mg daily, unless there is severe liver failure, then start at 5mg
Withdraw if creatinine >150mmols/l or eGFR < 30ml/1.73m ²	Review dose if renal function deteriorates and consider a switch to tolbutamide		Some gliptins can be used for all stages of renal disease	Withdraw if abdominal pain or pancreatitis develops	Withdraw if eGFR < 60ml/1.73m ²
Review if gastrointestinal disease is present or symptoms of nausea, heartburn, diarrhoea or flatulence are making patients miserable with discomfort	Review dose if liver function deteriorates as hypoglycaemia may occur	Should not be used in patients with or at risk of bladder tumour or heart failure	Combination with sulphonylurea increases the risk of hypoglycaemia		Limited evidence for use in people over 75 years old

- Doses may need to change if renal function declines; withdrawal of treatment may be necessary
- Hypoglycaemia risk will need to be reassessed with changes in eating patterns
- A change of insulin regimen may be needed to match changes in activity levels”
- Equipment for insulin delivery may need to be reassessed if physical capabilities alter, vision is poor, or carers become involved in giving insulin
- Evening isophane (Insulatard or Humulin I) in combination with daytime oral hypoglycaemic drugs may be a good first line treatment choice
- The simplest regimen should be chosen if switching to insulin only; both once or twice daily injection can be considered after discussion and agreement with the patient and their carers

Appendix 4: An End of Life Care Diabetes Management Flowchart

End of Life Diabetes Management



Key

Byetta (Exenatide) /Victoza, (Liraglutide), Lyxumia (Lixisenatide)

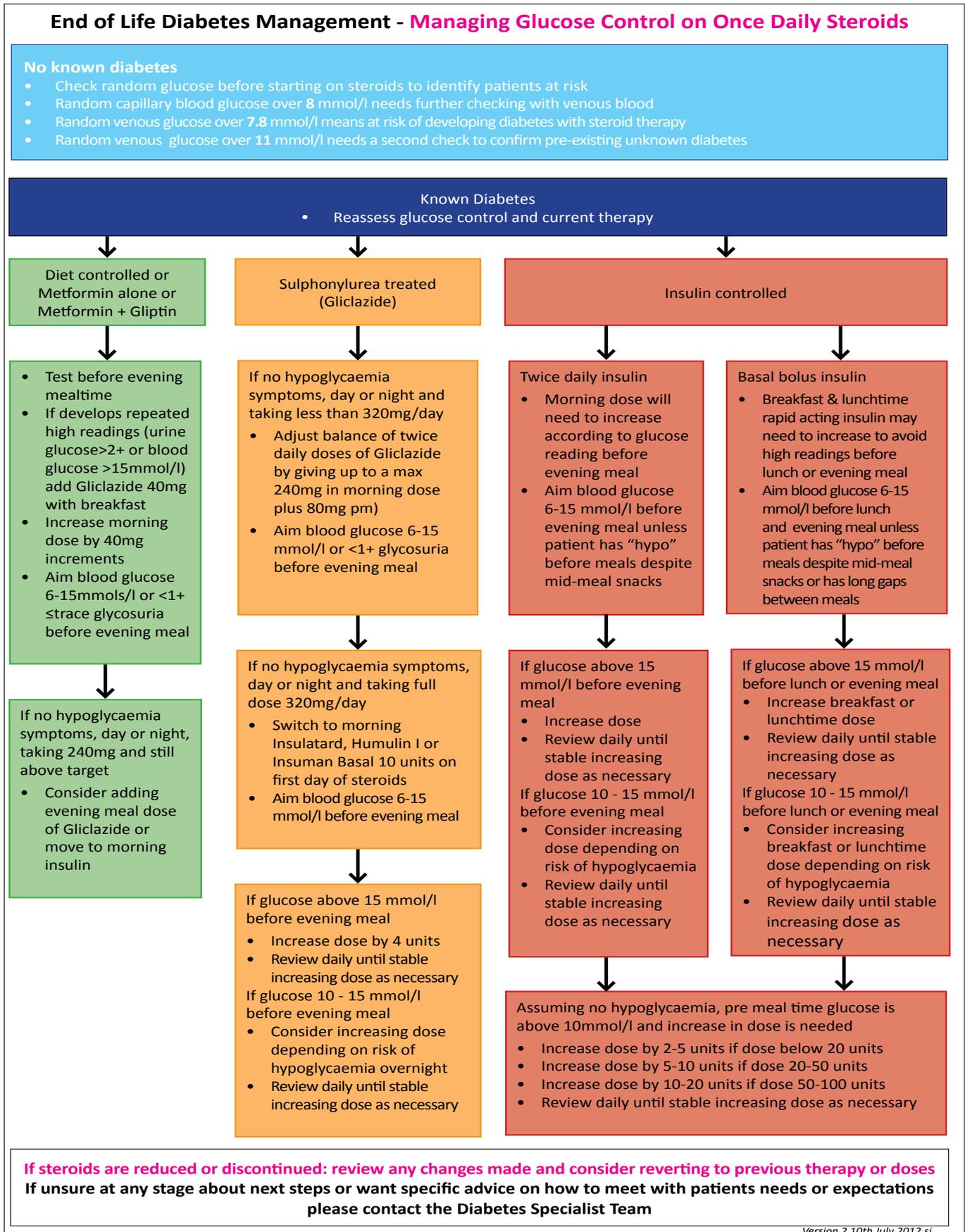
* Humalog/Novorapid®/Apidra

^ Humulin I /Insulatard/
Insuman Basal

- Keep tests to a minimum. It may be necessary to perform some tests to ensure unpleasant symptoms do not occur due to low or high blood glucose.
- It is difficult to identify symptoms due to “hypo” or hyperglycaemia in a dying patient.
- If symptoms are observed it could be due to abnormal blood glucose levels.
- Test urine or blood for glucose if the patient is symptomatic
- Observe for symptoms in previously insulin treated patient where insulin has been discontinued.

**For queries relating to the diabetes flowchart please contact the Diabetes Specialist Nurses
For queries relating to palliative care please contact the Palliative Care Team**

Appendix 5: A flowchart for Steroid Therapy



Appendix 6: Competencies in end of life diabetes care

COMPETENCIES IN END-OF-LIFE DIABETES CARE

These may be summarised as follows:

1. Unregistered practitioner	<ul style="list-style-type: none"> ● Undertake blood glucose monitoring and care as requested by registered nurse. ● Undertake blood or urine glucose and ketone monitoring as requested by registered nurse. ● Document and report the results according to local guidelines and protocols. ● Be aware of local policies relating to palliative/end of life care and diabetes. ● Be able to recognise signs and symptoms that may indicate hypoglycaemia or hyperglycaemia. ● Be able to offer suitable treatments for hypoglycaemia. ● Be able to offer appropriate alternative carbohydrate foods and drinks to replace meals.
2. Competent healthcare professional	<p>As 1, and:</p> <ul style="list-style-type: none"> ● Actively seek and participate in peer review of one's own practice. ● Assess the person's needs and ensure that symptoms of pain, dehydration and exhaustion from diabetes is minimised. ● Be aware that palliative care may vary in time and diabetes control needs to be assessed on an individual and a daily basis. ● Be aware that glucocorticoid steroids may cause diabetes which may need to be treated with insulin. Steroids may also worsen glycaemic control with pre-existing diabetes. ● Be aware that the aim of diabetes treatment in the last few days of life is to prevent discomfort from hypoglycaemia, hyperglycaemia, or diabetic ketoacidosis (DKA) in people with type 1 diabetes, with minimum intervention. ● Recognise that people with type 2 diabetes may not need treatment for diabetes in the last few days of life. ● Recognise that people with type 1 diabetes may need a change in insulin i.e. to a once-daily basal insulin, depending on the individual's eating pattern and choice. ● Be aware that food supplements like Fortisip may increase blood glucose levels and result in requiring a change in treatment.
3. Experienced healthcare professional	<p>As 2, and:</p> <ul style="list-style-type: none"> ● Initiate and develop personalised care plans including individual preferences and living wills in collaboration with the person with diabetes and their carers/family, appropriate to the imminence of their death. Ensure all information is documented and available to key stakeholders involved in the individual's care. ● Recognise when blood glucose-lowering and cardiovascular agents need to be adjusted or discontinued, in agreement with person with diabetes and their carers. ● Be aware of suitable leaflets about diabetes and end of life for patients and their carers/family. ● Give advice on blood glucose and ketone monitoring and, if required, the appropriate frequency of monitoring in agreement with person and carers. ● Devise appropriate synchronised glucose-lowering treatment schedules for peg feeds according to the individual's nutritional needs. ● Be aware of when diabetes deterioration requires hospitalisation.
4. Senior practitioner or expert healthcare professional	<p>As 3, and:</p> <ul style="list-style-type: none"> ● Plan, implement and deliver education programmes around diabetes and palliative care for other HCPs. ● If a registered medical or non-medical prescriber, adjust and prescribe medication related to diabetes, as required, within own competencies and scope of practice. ● Participate in the development of guidelines and protocols related to diabetes and palliative care. ● Support the self-management of insulin pump therapy and recognise when this should be discontinued
5. Consultant diabetologist or nurse	<p>As 4, and:</p> <ul style="list-style-type: none"> ● Work with stakeholders to develop and implement local guidelines for appropriate diabetes management at end of life, promoting evidence-based practice and cost-effectiveness. ● Lead on developing, auditing and reporting on patient-related experience and patient-related outcome measures and be able to produce information on the outcomes of diabetes care at end of life, including contributing to national data collection and audits. ● Initiate and lead research in diabetes management at end of life through leadership and consultancy. ● Identify service shortfalls in appropriate management of diabetes at end of life and develop strategies with the local commissioning bodies to address these. ● Identify the need for change, proactively generate practice innovations and lead new practice and service redesign solutions to better meet the needs of people with diabetes at end of life. ● Lead on liaising with local and national end-of-life networks and diabetes teams in the development of diabetes and end-of-life integrated care pathways, including the development of integrated IT solutions and systems for diabetes that record individual needs to support multi-disciplinary care across service boundaries. ● Influence national policy concerning appropriate management of someone with diabetes at the end of life. ● Work in collaboration with higher educational institutions and other education providers to meet educational needs of other HCPs.

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Adapted from *An Integrated Career and Competency Framework for Diabetes Nursing, 3rd Edition*

Appendix 7: Clinical Case Scenarios and Optimal Management

Practical Decision Making Towards the End of Life – Life stories

Case 1:

George's daughter, Caroline was very concerned about his diet and diabetes. Housebound with severe COPD needing home oxygen, he was too breathless and tired to eat much in one go. His diabetes control was poor on oral steroids, despite full dose gliclazide with metformin, so he was tending to be careful about his choice of foods. Deciding what he could eat was becoming a challenge and he was unhappy as he previously had good diabetes control. Caroline spoke to the Diabetes team for advice about his tablets.

Working with the practice team the agreed way forward was to accept the need for steroids and switch to insulin to manage the high glucose readings. Insulin would allow George more freedom around the choice of foods, with the introduction of nutritional supplements to help maintain his weight. George found insulin easier to manage than "swallowing all those tablets" and a twice daily isophane insulin with a higher dose in the morning gave better glucose control, reducing George's anxiety about having high readings.

Case 2:

Peter had coped with his diabetes during his chemotherapy and radiotherapy but admitted to his Macmillan Nurse that it was becoming a bit of a bother. He was eating only small amounts and was having difficulty balancing his 4 times daily insulin doses when in the past he had looked after his diabetes independently. She contacted the Diabetes Specialist nurse for advice.

In the last weeks of life and a limited appetite, aiming for his previous good control was unrealistic so she and Peter agreed different targets. Simplifying his insulin regimen by using short acting insulin with one meal a day and altering his long acting insulin timing gave a better match to his routine so he was able to reduce the number of home blood tests too.

As he weakened over the following weeks, he no longer needed mealtime insulin. His carers were able to keep him free of symptoms with once daily insulin Glargine.

Case 3:

Elsie had always struggled to manage her weight, but as her dementia worsened she became less interested in food and liable to miss meals. After her husband died the situation at home had become unsafe so she had been in residential care for some months. Although she seemed settled she was obviously frailer and needing increasing care.

Her GP visited after carers reported her increasing confusion and intermittently refusing tablets. He judged that some of the confusion could relate to low blood glucose as she had had one documented reading of 2.5mmol/l on testing.

On drug review he discontinued her gliclazide, switched to slow release metformin once daily and discontinued simvastatin. Giving metformin in the morning which was her "best time" was much easier for the carers to maintain concordance.

Swapping to urine testing gave her less distress and the aim was simply to keep her urine glucose below +, with HbA1C at 3 monthly intervals rather than home blood glucose testing.

Case 4:

Angela had been in and out of the Hospice in the last 3 months but was clearly in the last days of life on this admission, at times being barely rousable and no longer drinking. She had Type 1 diabetes since early childhood so her family were very worried about her missing insulin.

To avoid the risk of keto-acidosis her insulin Glargine was continued as a once daily but significantly reduced morning dose with late afternoon capillary testing to check she was in the target range which at that time was 15-20 mmols/l.

The family were reassured about the plan to avoid hypos and that the insulin she had needed nearly all of her life was being continued.

For the nursing staff it was good to know that doing a blood test was actually helping to keep her comfortable.

Appendix 8: Sick-Day Management for End of Life Care Guidance for Healthcare Professionals

A Guide for Healthcare Professionals

Sick Day Management for End of Life Diabetes Care (HCP)

A number of common precautions are often necessary to reduce the development of acute metabolic complications in people with diabetes during end of their life - Specific advice on treatment food intake and diabetes medication is provided in this leaflet, for Healthcare Professionals use only

Type 2 Diabetes: Specific Advice

1. Patients with Type 2 Diabetes on diet alone or tablets that are not sulphonylureas or prandial regulators

- Encourage the individual to take small sips of fluid regularly. (aim for 100ml per hour)
- Offer frequent small portions of easily digested foods or fluids e.g. soup, ice cream, milky drinks
- Observe for signs and symptoms of hyperglycaemia and dehydration
- Only check capillary blood glucose to confirm hyperglycaemia: aim to maintain blood glucose at 15mmol/l or less
- Consider stopping metformin if the patient has sickness/diarrhoea



2. Patients with Type 2 diabetes on a sulphonylurea, prandial regulator and/or insulin

- Check blood glucose only to confirm symptoms of hyperglycaemia or hypoglycaemia
- Offer frequent small easily digested carbohydrate foods to replace meals if unable to eat normally. Offer sips of sugar-free fluids, aiming for 100mls over an hour
- Consider increasing diabetes medications (if blood glucose levels above 15mmol/l) or reducing diabetes medication (if blood glucose levels less than 6mmol/l)
- Diabetes treatment may be discontinued if the patient is NOT eating and blood glucose level is less than 15mmol/l and patient is symptom-free

Type 1 Diabetes: Specific Advice

Patients with Type 1 Diabetes on insulin treatment appropriate measures include:

- Encourage the patient to sip sugar-free fluids regularly (aim for 100ml per hour)
- If unable to eat usual meals, offer frequent small portions of easily digested foods or fluids e.g. soup, ice cream, milky drinks
- Test for urine or blood ketones if patient has symptoms of hyperglycaemia and dehydration
- If ketones are present, test blood glucose and ketones 2 hourly:- continue usual insulin regimen (e.g. long-acting insulin daily) but add an additional 10% of current total average daily insulin dose as short-acting insulin (e.g. Humulin S, Apidra, NovoRapid) every 2 hours if ++ or greater on urine ketone strip or greater than 1.5mmol on blood ketone test. *
- If ketone levels do not improve, and the patient is vomiting, admit to hospital for intravenous insulin and rehydration

**Do not
discontinue
the long-acting
insulin**



* If this advice is not practical for those working in a community setting please contact the hospital team for advice

A Guide for Healthcare Professionals - Sick Day Management for End of Life Diabetes Care

Withdrawal of Treatment

Multiple factors may influence this process:

- Patient's wishes
- Dealing with concerns by family of a 'euthanasia' approach
- Advance decision to refuse treatment
- Intravenous/subcutaneous fluid or nasogastric feeding may be warranted for a brief spell

Close liaison with the patient, family and GP is warranted in this scenario.

Withdrawal of **part or whole of diabetes related treatment** can be considered under the following:

Conditions of withdrawal

1. When the patient is commenced on the Liverpool Care Pathway
2. Where frequent treatment-related hypoglycaemia is causing distress and significant management difficulties
3. Where continued treatment with insulin poses an unacceptable risk of hypoglycaemia or where the benefits of stricter glucose control cannot be justified
4. Where the tablet burden and side effects of blood pressure tablets and lipid lowering therapy outweigh any long term benefit
5. Where continued food or fluids is not the choice of the patient
6. Where prescribing anti-infective therapy is not likely to benefit the patient

Treating hypoglycaemia

If patient conscious and able to swallow give one of the following:	If patient conscious and unable to swallow, patients on PEG feeds: stop feed and insert one of the following:
150ml of non diet cola	30ml undiluted Ribena
200ml of pure smooth orange juice	150ml non-diet cola
100ml lucozade original	100ml lucozade original into the feeding tube
Once blood glucose is >4mmol/l give a starchy snack.	Repeat procedure every 5 mins until blood glucose >4mmol/l and resume feed.

Always seek advice from the Diabetes Specialist Team

End of Life Diabetes Care

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