

**DIABETES UK**  
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# End of Life Diabetes Care

A Strategy Document Commissioned by  
Diabetes UK

## Clinical Care Recommendations

Endorsed By:



## 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 pathway approaches, 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 comprises of two documents, the first clinical care recommendations and the second supporting information. Downloadable information sheets relating to staff competencies and a short guide for healthcare professionals relating to sick day rules are also included in the clinical care recommendations. These documents 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*

## **Members of the Steering Group**

### **June James**

Nurse Consultant in Diabetes, University Hospitals of Leicester NHS Trust TREND-UK, Clinical Nurse Lead (NHS Diabetes)

### **Elizabeth Kendrick**

GPwSI Older people County Durham & Darlington NHS Foundation Trust and Chair End of Life Clinical Innovation Team NHS North East

### **Angus Forbes**

FEND Professor of Diabetes Nursing, Kings College, London

### **Jill Hill**

Nurse Consultant in diabetes, Birmingham Community Healthcare NHS Trust TREND-UK

### **Jean MacLeod Co-Chair**

Consultant Physician and Diabetologist, North Tees and Hartlepool NHS Foundation Trust

### **Alan Sinclair Co-Chair**

Association of British Clinical Diabetologists, and Director, Institute of Diabetes for Older People (IDOP)

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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. This document aims to summarise a consistent but high quality approach towards end of life care for people with diabetes by providing a series of clinical care recommendations.

We have attempted to cover the major clinical problems that patients with diabetes at the end of life experience and how these best managed. This includes a review of the use of glucose-lowering therapies and what targets are appropriate to minimise hypoglycaemia and increase patient safety. We recognise that there are limitations to this approach such as 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 use these recommendations in developing their own local guidance and use this as a basis for developing clinical audit in this area.

## 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.

In Box 1 we define the **key purposes of our full Guidance Document:**

### Box 1

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 pathways, such as the Liverpool Care pathway

## 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 well-designed studies which support or provide insight into glucose regulation, diabetes self-management, or use of particular glucose-lowering therapies. This recommendation document was developed in partnership with multiple professional groups and forms a consensus of opinion.

## Principles of High Quality 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 in Box 2

### Box 2

- 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

## Management Goals in Key Clinical Areas

### 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.

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 glucose level **less** than 6 mmol/l

Aim 2 – no glucose level **higher** than 15 mmol/l

It should be remembered that many patients with existing diabetes will be aware of targets for control previously set and will need explanation and reassurance to agree a new set of values.

### Tailoring medication including the use of glucose -lowering therapies in end of life diabetes care

We have adopted 4 stages within the end of life scenario for considering the use of glucose-lowering therapies and other relevant drug therapies: these are colour coded in line with other nationally recognised stages of end of life care:

**Box 3****A - Blue “All” from diagnosis Stable with Year plus prognosis - box 3**

The use of cardio-protective therapies (e.g. ACE inhibitors, angiotensin-receptor blockers, aspirin, statins) should be reviewed in the light of the diagnosis and the presence of other medical co-morbidities, and dosage reductions (even withdrawal) of some of the therapies considered. Patients may experience more gastrointestinal effects from aspirin with poor dietary intake or concurrent steroid use. Patients on aspirin and steroids should be considered for gastro-intestinal protection with a proton-pump inhibitor or suitable alternative. Oral hypoglycaemic agents (OHAs) should be reviewed and the targets for glucose control agreed. Weight loss may mean a reduced need for OHAs or offer potential for simplifying regimens including insulin.

**Medicines Management Non Insulin therapies****Table 1:** Medicines management – Non insulin therapies

<b>Metformin (standard metformin or Glucophage SR®)</b>	<b>Sulphonylureas (gliclazide / glipizide / glimepiride)</b>	<b>Pioglitazone</b>	<b>Gliptins (sitagliptin / vildagliptin / saxagliptin / linagliptin)</b>	<b>GLP-1 analogues (exenatide or liraglutide)</b>
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
Withdraw if creatinine >150mmols/l or eGFR < 30ml/l/1.73m <sup>2</sup>	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
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	

**Medicines Management - Insulin therapies (Type 1 and Type 2 Diabetes)****Table 2:** Insulin therapies (Type 1 and Type 2 Diabetes)

Insulin (Type 1 and Type 2 Diabetes)
Doses may need to change with changes in renal function
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 / Humulin I, or Insuman Basal) 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

**Continuous sub-cutaneous insulin infusion by pump**

The use of insulin pumps is increasing, particularly among younger patients. The flexibility in dosing such equipment can offer is key to their success and can be exploited in the changing situations of palliative care as long as patients wish to be, and are capable of, using their own pump. The majority of patients using pumps will be well informed in managing the technical aspects of changing pump settings or altering insulin doses.

- Basal settings may be adapted to cope with predictable factors altering insulin requirements, such as the use of steroids or changing exercise levels
- Mealtime and correction boluses can be adapted to cope with diminishing appetite or “sick days”.
- Patients may need advice on the likely impact of their condition on their diabetes and insulin requirements.
- Close co-operation and early involvement of the Diabetes Specialist Team is to be encouraged.
- Even in the last days of life low basal settings can continue if carers and any professionals involved have the support needed from the Diabetes Team, regardless of the chosen place of care.

**Box 4**

**B - Green “Benefits” DS1500 Unstable / Advanced Disease Months prognosis - box 4**

At this stage the aim is to keep drug interventions to a minimum that will control symptoms. All of the above comments 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. The likelihood of carers being involved in insulin therapy increases at this stage and may inform the choice of insulin regime. If moving from twice daily to once daily insulin, the starting dose of glargine 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

**Box 5**

**C - Yellow “Continuing Care” Deteriorating Weeks prognosis - box 5**

Patients may present at this stage, in which case all of the suggested changes above should be considered but keeping in mind that there may be little time to get used to 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”

### Patients with problems swallowing or poor appetite

Changes in meal size or frequency can have a significant impact on glucose levels. 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 appropriate 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 which may well have an adverse impact on glucose levels. Adjusting medication is preferable to limiting the diet but therapy will have to match small frequent meals.

- Metformin is available in powdered form or syrup or for patients not coping with tablets. If possible use the powdered form as metformin syrup is much more expensive and has a shorter shelf life so repeated prescriptions are required.
- Avoid long-acting sulphonylurea preparations (glibenclamide, gliclazide, glipizide glimepiride) if small meals are being taken
- Repaglinide 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

### Box 6

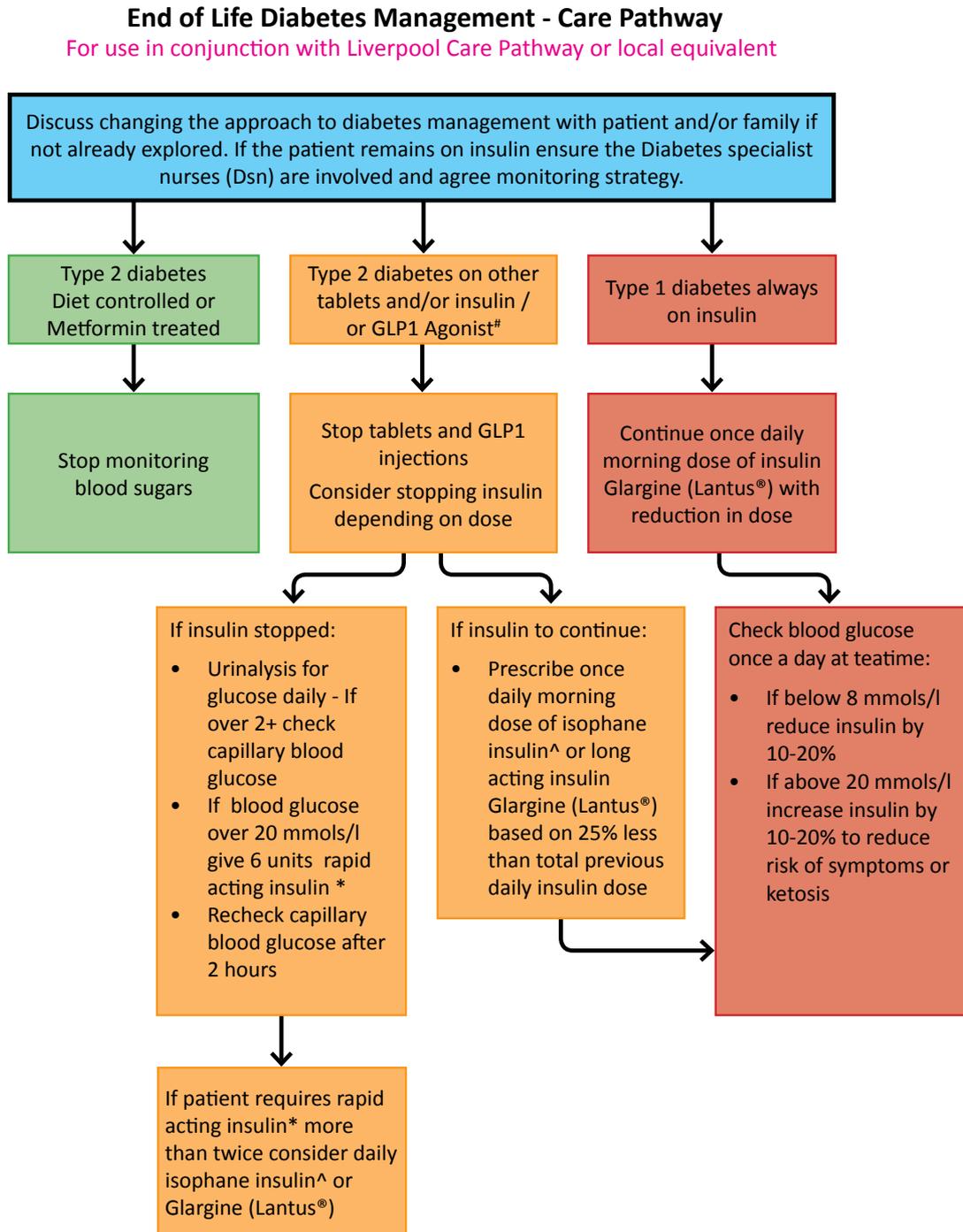
#### D - Red "Days" Final days / Terminal Care Days prognosis - box 6

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 bedbound, semi-comatose, no longer able to take tablets, no longer able to eat and only able to take sips of fluid, use of the Liverpool Care Pathway (LCP) or a local alternative such as "Deciding Right" should be considered.

At this stage, the **Flowchart for Diabetes at End of Life** describes how to manage diabetes in the dying patient and complements the LCP. It can be reassuring for relatives and carers to know that this additional pathway 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 and keep invasive testing to the minimum needed to achieve that aim.

Fig 1 - A flowchart for an end of life diabetes care management strategy is given below:



# Byetta (Exenatide) /Victoza (Liraglutide)

\* 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.

Contact the Diabetes Specialist Nurses or Palliative Care Team if advice required

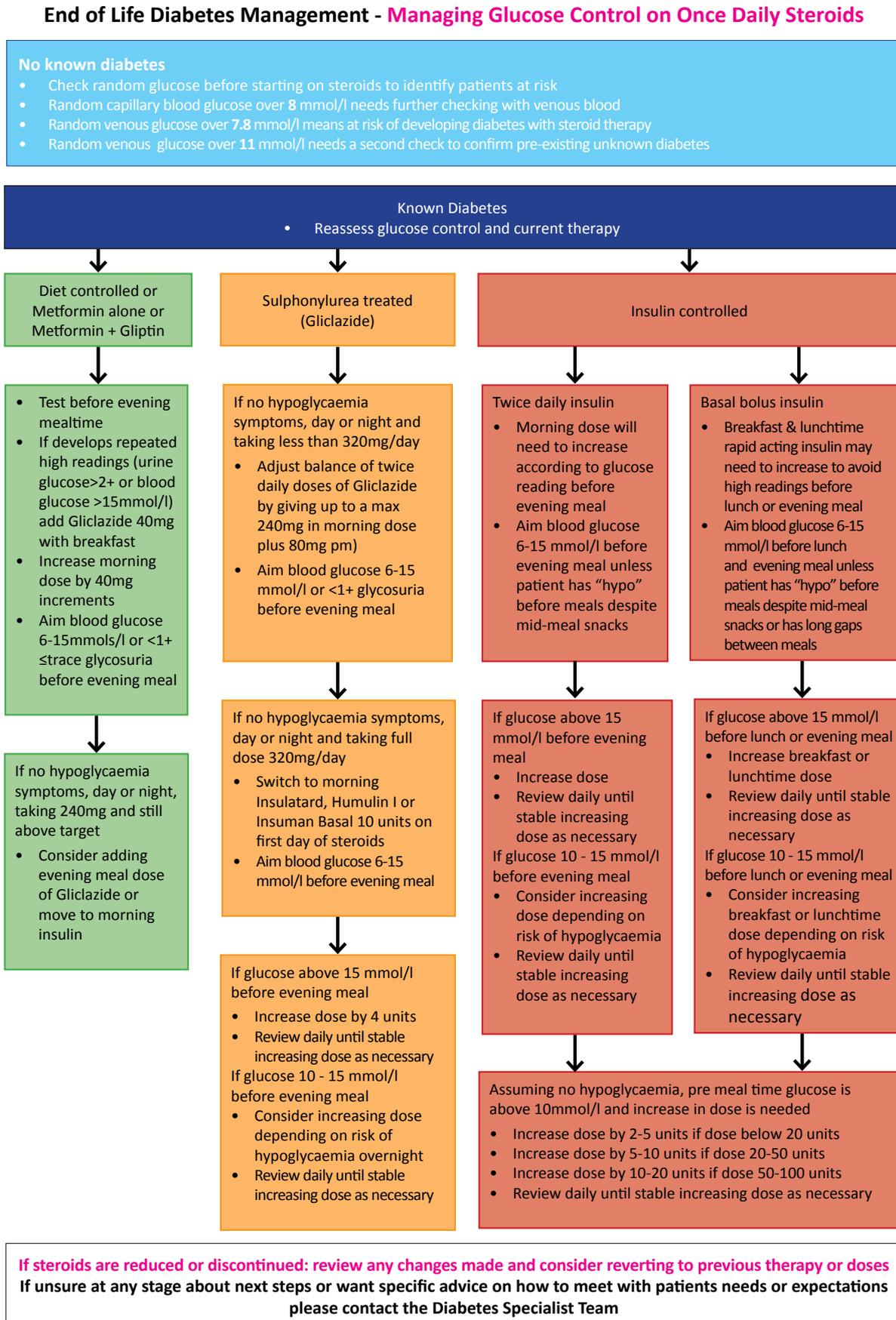
## **Managing the Effects of Steroid Therapy**

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). Please see algorithm on page 14 for managing patients on once daily steroid.

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 insulin regimen (e.g. Humulin I/Insulatard or Insuman Basal given once daily) should be considered. Liaison with a community dietitian may assist in meal planning.

Fig 2 - Algorithm for Managing Glucose with Once Daily Steroid.



## Hypoglycaemia Management

Hypoglycaemia can be troublesome at any time in patients 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
- Tailor insulin therapy and avoid 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

### Identifying those at risk:

These include all insulin, sulphonylurea (e.g. gliclazide, glipizide, glimepiride) and prandial regulator users (Nateglinide, 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

### Identifying hypoglycaemia: signs and symptoms

The patient may feel one or more of the following symptoms listed in Box 7:

#### Box 7

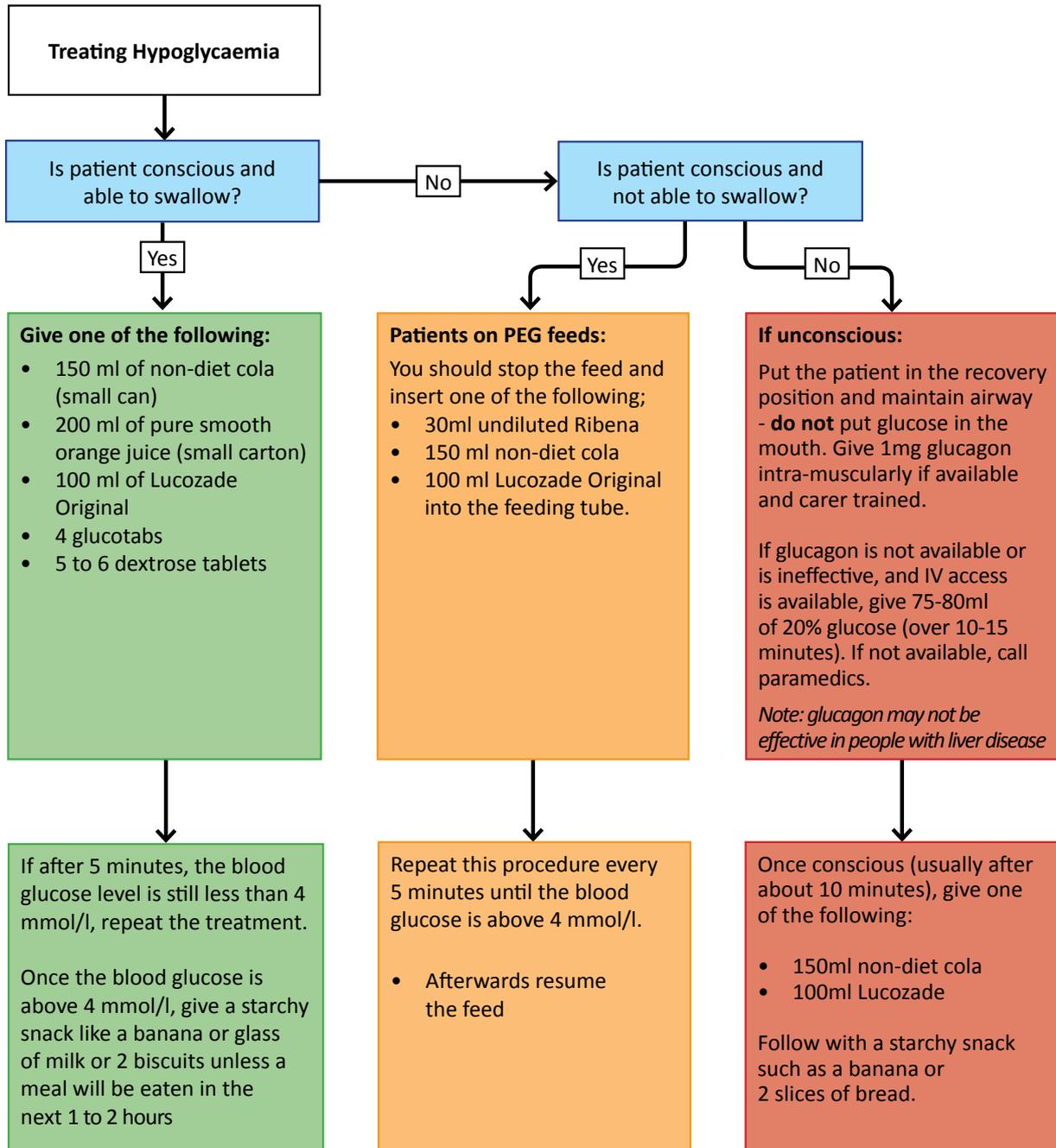
##### Symptoms of Hypoglycaemia

- 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

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. An algorithm of hypoglycaemia management has been provide on page 16.

Fig 3 - Algorithm for treating hypoglycaemia:

End of Life Diabetes Management - **Treating Hypoglycaemia**



**After an episode of hypoglycaemia:**  
 Consider discontinuing insulin (unless Type 1 diabetes) or reducing insulin or oral hypoglycaemia agents.  
 Review management plan with patient and relatives to clarify/confirm goals of diabetes management for their stage of life.

## 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 3:

**Table 3: Type 2 Diabetes: Specific Advice**

Type 2 on diet alone or tablets that are not sulphonylureas 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 4: 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 ( <i>please see sick day rules</i> )

## Withdrawal of Treatment

Withdrawal of part or whole of diabetes-related treatment can be considered under 6 conditions listed in Box 8:

### Box 8

- 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.

**Fig 4: Example of Sick-Day Management for End of Life Care Guidance for Healthcare Professionals information Leaflet**

## 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**



Produced in cooperation with:



## Key Action Points

These clinical care recommendations complement the larger more comprehensive document that we have produced which forms a template for a national End of Life Diabetes Care Strategy. It is important to emphasise the following:

- Balance benefits of diabetes interventions with prognosis/estimated time of life left
- As end of life approaches minimise interventions and monitoring to keep the patient comfortable without compromising safety (ie avoid metabolic complications)
- Involve patient and family in decisions about diabetes management
- Diabetes management requirements can change quickly with steroid use, weight loss, liver disease etc...so involve the diabetes specialist nurse and dietitian especially if the patient has Type 1 diabetes or Type 2 treated with insulin.

## References and Resources – taken from the supporting document on end of life diabetes care

### 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] Diabetes and End of Life Care, Association of British Clinical Diabetologists Position Statement, 2010
- [3] Mitchell G (2003) How well do General practitioners deliver palliative care? A systematic review. *Pall Med* 16. 457-464
- [4] Roach MS (1992) *The Human Act of Caring: A blueprint for the Health Professions*. 2<sup>nd</sup> edn. Canadian Hospital Association Press, Ottawa

### Supporting:

- Angelo M, Ruchalski C, Sproge BJ. An approach to diabetes mellitus in hospice and palliative medicine. *J Palliat Med*. 2011 Jan;14(1):83-7
- 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
- Poulson J. The management of diabetes in patients with advanced cancer. *J Pain Symptom Management* 1997; 13:339-46
- 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](#). *Nurs Times*. 2005 Apr 26-May 2;101(17):30-2.
- TREND-UK (2011) *An Integrated Career and Competency Framework for Diabetes Nursing 3<sup>rd</sup> edn*. SB Communications Group, London available on [www.trend-uk.org](http://www.trend-uk.org)
- Vandenhoute V. Palliative care and type II diabetes: A need for new guidelines? [Am J 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](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](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](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](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](http://www.palliativecarescotland.org.uk/publications/Palliative%20and%20End%20of%20Life%20Care%20in%20)

## Appendix

### Appendix 1: Staff competencies in end of life care

## COMPETENCIES IN END-OF-LIFE DIABETES CARE

These may be summarised as follows:

<p><b>1. Unregistered practitioner</b></p>	<ul style="list-style-type: none"> <li>● Undertake blood glucose monitoring and care as requested by registered nurse.</li> <li>● Undertake blood or urine glucose and ketone monitoring as requested by registered nurse.</li> <li>● Document and report the results according to local guidelines and protocols.</li> <li>● Be aware of local policies relating to palliative/end of life care and diabetes.</li> <li>● Be able to recognise signs and symptoms that may indicate hypoglycaemia or hyperglycaemia.</li> <li>● Be able to offer suitable treatments for hypoglycaemia.</li> <li>● Be able to offer appropriate alternative carbohydrate foods and drinks to replace meals.</li> </ul>
<p><b>2. Competent healthcare professional</b></p>	<p>As 1, and:</p> <ul style="list-style-type: none"> <li>● Actively seek and participate in peer review of one's own practice.</li> <li>● Assess the person's needs and ensure that symptoms of pain, dehydration and exhaustion from diabetes is minimised.</li> <li>● Be aware that palliative care may vary in time and diabetes control needs to be assessed on an individual and a daily basis.</li> <li>● 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.</li> <li>● 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.</li> <li>● Recognise that people with type 2 diabetes may not need treatment for diabetes in the last few days of life.</li> <li>● 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.</li> <li>● Be aware that food supplements like Fortisip may increase blood glucose levels and result in requiring a change in treatment.</li> </ul>
<p><b>3. Experienced healthcare professional</b></p>	<p>As 2, and:</p> <ul style="list-style-type: none"> <li>● 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.</li> <li>● Recognise when blood glucose-lowering and cardiovascular agents need to be adjusted or discontinued, in agreement with person with diabetes and their carers.</li> <li>● Be aware of suitable leaflets about diabetes and end of life for patients and their carers/family.</li> <li>● Give advice on blood glucose and ketone monitoring and, if required, the appropriate frequency of monitoring in agreement with person and carers.</li> <li>● Devise appropriate synchronised glucose-lowering treatment schedules for peg feeds according to the individual's nutritional needs.</li> <li>● Be aware of when diabetes deterioration requires hospitalisation.</li> </ul>
<p><b>4. Senior practitioner or expert healthcare professional</b></p>	<p>As 3, and:</p> <ul style="list-style-type: none"> <li>● Plan, implement and deliver education programmes around diabetes and palliative care for other HCPs.</li> <li>● If a registered medical or non-medical prescriber, adjust and prescribe medication related to diabetes, as required, within own competencies and scope of practice.</li> <li>● Participate in the development of guidelines and protocols related to diabetes and palliative care.</li> <li>● Support the self-management of insulin pump therapy and recognise when this should be discontinued</li> </ul>
<p><b>5. Consultant diabetologist or nurse</b></p>	<p>As 4, and:</p> <ul style="list-style-type: none"> <li>● Work with stakeholders to develop and implement local guidelines for appropriate diabetes management at end of life, promoting evidence-based practice and cost-effectiveness.</li> <li>● 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.</li> <li>● Initiate and lead research in diabetes management at end of life through leadership and consultancy.</li> <li>● Identify service shortfalls in appropriate management of diabetes at end of life and develop strategies with the local commissioning bodies to address these.</li> <li>● 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.</li> <li>● 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.</li> <li>● Influence national policy concerning appropriate management of someone with diabetes at the end of life.</li> <li>● Work in collaboration with higher educational institutions and other education providers to meet educational needs of other HCPs.</li> </ul>

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

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