

Commissioned by: **DiABETES UK**  
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# END OF LIFE DIABETES CARE

## Clinical Care Recommendations

3rd Edition March 2018

Developed by:



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Guideline endorsed by:



# WELCOME & STATEMENTS

Managing diabetes is an added stress for those who are nearing the end of their life and for their families. The special issues and challenges of diabetes can make this emotional time harder to manage for everyone involved. Yet there remain inconsistencies in the services and support available across the UK. These updated guidelines provide health and social care professionals with a valuable resource to help improve the quality of care delivered to meet the personal preferences and priorities of those who are dying, their families and carers, thereby helping them to live as well as possible until they die.

## **Bridget Turner**

Director of Policy and Care Improvement

**Diabetes UK**

I welcome the publication of these clinical care recommendations. Improving the care of people with diabetes throughout their life right up to the time they die is critically important for their overall experience and quality of life, and that of those who are important to them. These recommendations contribute towards achieving the Ambitions for Palliative and End of Life Care ([www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk)) which includes the ambition to maximise comfort and well-being and to ensure that everyone has fair access to care. These recommendations also support the government's 6 point commitment to people who are approaching the end of their lives<sup>(1)</sup>, which include that they would be given opportunity and support to have honest conversations, make informed decisions and be able to develop, document and share their personalised care plan, involving those who are close to them to the extent that they wish.

## **Professor Bee Wee**

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National Clinical Director for End of Life Care

**NHS England**

Living with diabetes may at times be difficult, but it is highly important that we recognise and effectively manage the specific challenges that it poses at the end of life. End of life care in those with diabetes is underpinned by a holistic approach to management; it is not just about dealing with blood glucose but encompasses many other aspects of care, such as nutrition, hydration, skin care and recognising the impact of frailty. The care of people dying with diabetes demands a multidisciplinary approach with healthcare professionals coming together with the person with diabetes, their family and their carers to formulate and deliver a plan for management through all the phases of dying. The third edition of the End of Life Diabetes Care document is therefore welcome, as it guides clinicians to deliver the best care possible to support people living with diabetes until they die.

## **Professor Jonathan Valabhji**

National Clinical Director for Diabetes and Obesity

**NHS England**

## PREFACE TO THE THIRD EDITION

Individuals 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.

**It is estimated that 4.9 million people worldwide died in 2014. In the UK it is estimated that each year 500,000 people die and 75,000 of these will have diabetes**

The causes of death in people with diabetes are in general the same as for those without diabetes, but cardiovascular deaths (especially heart failure) and certain cancers are over-represented. Diabetes has a higher prevalence in older people; 10-30% of European people of pensionable age and 25% of care home residents in the UK are known to have diabetes. People with diabetes are at greater risk of dying earlier than those without diabetes but only a minority of deaths in people with diabetes are directly attributable to diabetes.

This timely revision of the original document has been necessary in view of changing developments in end of life care policy, the need to address special populations of those with diabetes, the introduction of newer therapies to control blood glucose, and also as a response to the many constructive comments and feedback from practising clinicians in the field about our earlier revision. As before, our approach has been to develop a consensus of key recommendations that provide practical and compassionate advice on the care of people with diabetes at the end of life.

Diabetes care at the end of life should not influence individual, carer or professional preference for place of care. Generic guidance on end of life care applies to people dying with diabetes and healthcare professionals need to be trained and competent to care for this population. We have provided an additional section on training and education of the healthcare workforce to emphasise the importance of this.

This updated guidance summarises the major clinical problems that individuals with diabetes at the end of life experience and how these are best managed. We have provided additional information on the early identification of those entering an end of life scenario, a new section on special populations such as those who are frail or demented, or residing in a care home, additional guidance relating to those with cancer and renal failure on dialysis, and updated our guidance on advance care directives. We have also revised our information on glucose-lowering therapies including the newer insulin analogues.

We continue to recognise the limitation to this type of document as there are considerable shortfalls in the levels of research evidence to support high quality evidence-based recommendations. As such, we hope you will also accept this document as a summary of best clinical practice in this important but often under-represented area in everyday clinical diabetes care. We anticipate that health and social care professionals may wish to use this resource to guide their local development of end of life diabetes care policies and stimulate multi professional clinical audit in this area.

**Professor Alan Sinclair**

## STEERING GROUP

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With thanks to Michael Bonar and Shehnaz Jamal (Leicester Diabetes Centre) for their creative directions and helpful contributions to flowcharts and table designs.

## INTRODUCTION



### DEFINITION:

Individuals are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes individuals whose death is imminent (expected within a few hours or days) and those with:

- a. Advanced, progressive, incurable conditions
- b. General frailty and co-existing conditions that mean they are expected to die within 12 months
- c. Existing conditions from which they are at risk of dying from a sudden acute crisis in their condition
- d. Life-threatening acute conditions caused by sudden catastrophic events

[http://www.gmc-uk.org/static/documents/content/Treatment\\_and\\_care\\_towards\\_the\\_end\\_of\\_life\\_-\\_English\\_1015.pdf](http://www.gmc-uk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_1015.pdf)

### Early Identification

The Gold Standards Framework<sup>(2)</sup> for end of life care proposed three triggers that may help the health care professional to determine if the individual is nearing the end of life:

1. **The “Surprise Question”: ‘Would you be surprised if this individual were to die in the next few months, weeks, days?’**

The answer to this question should pull together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then it is important to consider what measures might be taken to improve the individual’s quality of life now and in preparation for possible further decline.

## 2. General indicators of decline - deterioration, increasing need or choice for no further active care.

These include:

- Decreasing activity –functional performance status, declining limited self-care, in bed or chair 50% of day and increasing dependence in most activities of daily living
- Co-morbidity which is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support, advanced disease with an unstable, deteriorating complex symptom burden
- Decreasing response to treatments
- Decreasing reversibility
- Individual choice of no further active treatment e.g. to come off renal replacement therapy
- Progressive weight loss (>10%) in past six months
- Repeated unplanned or crisis admissions
- Sentinel event e.g. serious fall, bereavement, transfer to nursing home.
- Serum albumin less than 25g/L
- Considered eligible for additional financial support and benefits

## 3. Specific clinical indicators related to certain conditions.

These relate to specific conditions. Although diabetes is not mentioned, it frequently occurs in association with those conditions that are specifically mentioned including cancer, chronic obstructive airways disease, heart disease, renal disease, general and specific neurological disease, such as motor neurone disease, Parkinson's disease and multiple sclerosis, frailty, dementia and stroke.

The Gold standards framework also defines 4 main phases of illness:

- a. Stable from diagnosis (usually lasting years)
- b. Unstable, advanced disease (usually lasting months)
- c. Deteriorating, exacerbations (usually lasting weeks)
- d. Last days of life (usually lasting days)

### ➤ See Appendix 1 for Proactive Identification Guidance

This model has been adapted in Canada, Australia and New Zealand and their guidance is separated into 5 stages as they included death and bereavement which is considered an integral part of care provision

1. Disease advancement
2. Experiencing life limiting illness
3. Dependency and symptom increase
4. Decline and last days
5. Death and bereavement

For people with diabetes who are taking insulin or  $\beta$ -cell secretagogues, we recommend adding hypoglycaemia to the indicators that a person is at the end of life. It has long been recognised that the development of hypoglycaemia in people who have not previously been prone to this is a poor prognostic sign. This is true for hospitalised individuals, in whom the excess mortality is not caused by hypoglycaemia per se, but by associated co-morbidities. It seems that this also applies to out-of-hospital hypoglycaemia<sup>(3)</sup>.

### The management of diabetes at the end of life

The care of the dying person with diabetes is challenging, encompassing changes to:

- Glycaemic targets
- Individual and carer expectation
- Reducing risk of hyperglycaemia and hypoglycaemia
- Managing the effects of other medications such as glucocorticosteroids
- Tailoring of diabetes medications

This will depend on the phase of illness. Planning for end of life care in people with diabetes is often seen as a direct choice between treating or withdrawal of treatment for diabetes; in practice caring for the dying individual is more complex.

## Purpose of this Guidance

This document is primarily aimed at all those within the health and social care workforce who care for people living with diabetes and their families during the last year of life.

Key purpose of our full guidance document is to:

- Describe a consistent high quality approach towards end of life diabetes care
- Provide 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
- Highlight the awareness of training and educational needs for high quality end of life diabetes care
- Foster partnerships in end of life diabetes care training, competencies with established Palliative Care planning





## Principles of High Quality Diabetes Care at the End of Life

These are to:

- Ensure that effective symptom control is provided during the dying stage
- 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
- Avoid foot complications and pressure sores in frail, bed-bound individuals with diabetes
- Avoid symptomatic clinical dehydration
- Provide an appropriate level of intervention according to stage of illness, symptom profile, and respect for dignity
- Support and maintain the empowerment of the individuals (in their diabetes self-management) and carer for as long as possible

## 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 the illness, ability of the individual 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 in those who are taking glucose lowering therapies and/or insulin where there may be a risk of hypoglycaemia. People on no pharmacological therapy or Metformin alone should not be at risk of hypoglycaemia. Those on DPP4 inhibitors are at low risk of hypoglycaemia.

- **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 individuals 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.

Specific recommendations which are aligned to life expectancy are given in the UK guidelines. In general, non-insulin glucose lowering therapies can be reduced and eventually stopped depending on other factors such as poor appetite, weight loss, anorexia. It may be necessary to discontinue insulin treatment in people with type 2 diabetes, but insulin should never be stopped in those known to have type 1 diabetes.

### Other Medication

Once it has been recognised that a person has reached end of life a review of all prescribed medication is indicated. Many people with diabetes are taking medication intended to reduce the risk of cardiovascular events in the long term, including ACE inhibitors or angiotensin II receptor antagonists, other anti-hypertensives, aspirin or anti platelet agents, statins and other lipid-lowering agents. There are significant potential side-effects and tablet burdens associated with these medicines, and stopping some or all of them may improve quality of life. This decision should be taken in conjunction with the individual and their family to avoid giving the impression that their medical advisors are 'giving up on them'.

## MEDICATION

### Tailoring Medication Including the Use of Glucose Lowering Therapies in End of Life Diabetes Care

We have adopted **four stages (A - D from the Gold Standards Framework)** 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:

➤ **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**

➤ **A - Blue “All” from diagnosis stable with year plus prognosis**

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.

Individuals may experience more gastrointestinal effects from aspirin with poor dietary intake or concurrent steroid use. Individuals on aspirin and steroids should be considered for gastro-intestinal protection with a proton-pump inhibitor or suitable alternative.

Oral hypoglycaemic agents (OHAs) and or insulin should be reviewed and the targets for glucose control agreed. Weight loss may mean a reduced need for OHAs and/ or insulin or offer potential for simplification of the glucose control regimen.

## Medicines Management Non - Insulin therapies

Individuals with type 2 diabetes typically progress from diet alone to treatment with a single oral agent (usually metformin) to treatment with two or three different agents in combination at intensification steps defined by their HbA1c. Applying the principle of individualised care means that at the diagnosis of end of life, a review of the prescribed medicines is indicated. This will minimise the risk of side effects, while keeping the individual free of symptomatic hyperglycaemia, which will include a discussion about revised glycaemic targets. As appetite reduces and weight drops, agents such as GLP 1-RA or SGLT2i's that promote satiety and weight reduction may no longer be required. If maintaining hydration is a problem, agents with a diuretic effect may be inappropriate. Not all agents when used alone cause hypoglycaemia, and this may be an important factor in deciding what to use.

**Table 1: Medicines Management – Non - Insulin therapies**

Metformin (Standard Metformin or Glucophage SR®)	Sulphonylureas (Gliclazide / Glipizide / Glimpiride / Repaglinide)	Pioglitazone	Gliptins (Alogliptin, Linagliptin, Saxagliptin, Sitagliptin)	GLP-1 analogues (Exenatide or Liraglutide, Lixisenatide, Bydureon and Dulaglutide)	Sodium Glucose Co-Transporter 2 Agents (SGLT2) Dapagliflozin and Canagliflozin
<b>Risk of hypoglycaemia with non insulin therapies when used as mono therapy</b>					
<b>✗ No Risk</b>	<b>✓ Moderate Risk</b>	<b>✗ No Risk</b>	<b>✓ Low risk</b>	<b>✗ No risk</b>	<b>✓ Low risk</b>
<b>General Considerations</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 individuals 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	Refer to SPC* for doses
Withdraw if creatinine >150mmols/l or eGFR < 30ml/1.73m <sup>2</sup>	Review dose if renal or liver 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	Refer to individual SPC* for renal guidance
Review if gastrointestinal disease is present or symptoms of nausea, heartburn, diarrhoea or flatulence are making individuals miserable with discomfort	Review Tolbutamide dose if liver function deteriorates as hypoglycaemia may occur	Should not be used in individuals with or at risk of bladder tumour or heart failure	Combination with sulphonylurea increases the risk of hypoglycaemia	Refer to individual product SPC* for doses.	Stop if evidence of clinical dehydration peripheral vascular disease/ foot ulceration in acute illness and pre-surgery. Test for ketones if there is acute illness

\* Summary of product characteristics

## Medicines Management - Insulin therapies (Type 1 and Type 2 Diabetes)

Individuals with type 1 diabetes have an absolute requirement for insulin treatment, without which they will rapidly become hyperglycaemic and develop diabetic ketoacidosis. In contrast, most individuals with type 2 diabetes who are prescribed insulin continue to produce some endogenous insulin that protects them from ketoacidosis if it is stopped. Some will develop hyperosmolar hyperglycaemic state, particularly if given corticosteroids. It follows that it is important to know what type of diabetes the individual has in order to provide best advice. Insulin dose requirements will change at end of life. As appetite reduces and weight falls the amount of insulin needed to control blood glucose will fall. A discussion about target glucose and aims of treatment should be had early on, so that individuals and their families understand that dose reductions are likely. As food intake drops it is likely that fast-acting insulin can be discontinued, and basal insulin will suffice, even for people with type 1 diabetes. Some individuals with type 2 diabetes may achieve their revised targets without insulin injections, but insulin should be continued for those with type 1 diabetes. If the individual is unable to manage their own injections, it will be necessary for a carer or visiting health care professional to do it. It is suggested that one capillary blood test per day is performed just before the insulin dose is administered to ensure it is in the target range and there is no hypoglycaemia.

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

- Doses may need to change with changes in renal function including those in renal replacement therapy
- 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) (cloudy insulin) in combination with daytime oral hypoglycaemic drugs may be a good first line treatment choice in individuals with type 2 diabetes
- The simplest regimen should be chosen if switching to insulin only; both once or twice daily injection can be considered
- Consider using an analogue basal insulin if the individual is at high risk of hypoglycaemia
- **Do not stop insulin in individuals with type 1 diabetes**

➤ See Appendix 2 for Insulin Table

## Continuous subcutaneous insulin infusion (Insulin Pump Treatment)

The use of insulin pumps by people with type 1 diabetes is becoming increasingly common. The majority of users are competent in managing their diabetes, relying on frequent capillary blood glucose tests and adjusting bolus doses according to the carbohydrate content of their food. The technology offers a flexibility to respond to the changing insulin requirements at the end of life, providing the individual or carers have the skills and support to use it.

Individuals will need advice about the likely impact of their condition on their diabetes, so early involvement of the Diabetes Specialist Pump Team is desirable. A different approach to glucose targets may be appropriate, with an emphasis on safety and avoidance of hypoglycaemia rather than achieving tight control. A range of basal insulin profiles should be made available in anticipation of changing insulin requirements due to weight loss (dose reduction), corticosteroid treatment (increased dose). Mealtime and correction boluses will need to be adjusted to reflect predictable changes in insulin sensitivity, and to address the effects of diminishing appetite.

A minority of patients use continuous glucose monitoring with a low glucose alarm or low glucose insulin suspend function in conjunction with their pump (sensor augmented pumps). This is an additional safety feature that reduces the risk of severe hypoglycaemia in patients who have hypoglycaemia unawareness. Patients with such technology should continue to use it providing that they and their carers are prepared to perform the necessary calibration capillary blood glucose tests. While frequent alarms in the low normal glucose range may cause undue distress, the insulin suspend feature may provide reassurance.

Even in the last days of life when the individual is eating little or nothing, and is no longer able to manage their own pump, it can be used to deliver their basal insulin requirements if carers have the necessary competencies and support from the Diabetes Specialist Pump Team in their chosen place of care. If at anytime the individual wishes to stop using their insulin pump, it should be removed one hour after a subcutaneous dose of basal insulin has been given. Fast acting insulin should be prescribed as necessary. The pump should be stored securely and returned to the Pump Team in due course.

### Flash Glucose Monitoring

Increasingly individuals are using FreeStyle Libre® flash glucose monitoring as a more convenient method to manage their diabetes. This employs a pre-calibrated sensor that measures the tissue glucose concentration repeatedly for two weeks. Results, latest glucose concentration and trend direction, are obtained by scanning the sensor with a reader. There is no limit to the number of readings that can be obtained from a single sensor. Since one indication for this technology is when a third party is managing diabetes for an individual, it need not be stopped at the end of life providing those using it have been trained in its use.

➤ **B - Green “Benefits” Unstable / Advanced Disease  
Months prognosis**

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 individuals are on combinations of oral hypoglycaemic agents with insulin. It is generally simpler for individuals 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 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” Deteriorating Weeks prognosis**

Individuals may present or be referred to the diabetes team at this time, 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 individuals 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”.



### ➤ D - Red “Days” Final days / Terminal Care 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 individual is bed bound, semi-comatose, no longer able to take tablets, no longer able to eat and only able to take sips of fluid. The use of a local protocol or advice from the specialist team may guide your decision making.

At this stage, the Flowchart for Diabetes at End of Life (Fig 1 page 23) , describes how to manage diabetes in the dying individual. 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 and keep invasive testing to the minimum needed to achieve that aim.



## VULNERABLE SPECIAL POPULATIONS

Modern end of life care strategies have a set of principles that apply to all individuals in this category such as relief of unpleasant symptoms, preventing further declines in quality of life (and enhancing it where possible), and respecting a person's choices, culture, beliefs, and place of dying. Unfortunately, those who are often unable to communicate effectively or who are severely frail or disabled and therefore highly dependent, cannot always be managed knowing that these special needs are being met. They represent a key challenge for all health professionals.

### Care Home residents

Residents with diabetes have a high prevalence of associated medical co-morbidity, dementia, frailty and disability<sup>(4)</sup>. Diabetes doubles the risk of admission to care home and accounts for about 26% of residents irrespective of whether they are in a residential or nursing home<sup>(5)</sup>. Admission to a care home is considered an important prognostic indicator for future end of life care, and the majority of care home residents with diabetes would be considered to be in their terminal phase of life<sup>(6)</sup>. Whilst diabetes care in care home settings may be less than optimal, the provision of high quality standards in end of life diabetes care is also likely to be poor, and requires urgent action to address these shortfalls<sup>(7)</sup>.

### Frailty

Diabetes is independently associated with frailty and 40% or more people with diabetes aged 80 years are frail<sup>(8)</sup>. The presence of frailty increases the risk of reduced mobility, functional decline and decreased survival<sup>(9)</sup> and may be an important factor in many people with diabetes entering an end of life phase. Deterioration in health and well-being in frail older people can be slowly progressive and the onset of a terminal phase may be difficult to diagnose<sup>(10)</sup>. An acute event such as pneumonia or a stroke can accelerate this decline.

Frailty also increases the risk of delirium, falls, and social withdrawal and it is imperative that health professionals involved in the direct care of those at end of life are able to identify the features of frailty and how to minimise these developments.





## Detection of Frailty

In an end of life scenario, it may be important to determine whether someone is frail or not in order to assist diabetes management goals. This should also allow more appropriate and safer treatment strategies to be employed. Screening for frailty in these circumstances should impose a minimum of health professional time and not require the individual at end of life to be engaged in tedious or long procedures. The FRAIL test developed in both Europe and the United States has now been extensively validated across the Globe. It is a 5-item FRAIL questionnaire (Fatigue, Resistance, Ambulation, Illnesses, & Loss of Weight), which is easy to employ and is an excellent predictor of further functional decline and subsequent mortality. Further information is available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4515112/>

## Dementia

Diabetes increases the risk of cognitive impairment in someone living with dementia<sup>(11)</sup> which may lead to poorer concordance to therapy, a worsening of glucose control, increased risk of hypoglycaemia, and increasing need for assistance with care. The diagnosis of dementia should prompt a clinician to include an end of life care plan in the overall care strategy. Poor nutrition and the inability to undertake usual diabetes regimens are a common feature as dementia symptoms worsen. The course of someone with both diabetes and dementia is often one of slow decline in health status, increasing risk of frailty, and increased vulnerability to infections.

However, in cases of advanced dementia, certain signs and symptoms may point to someone nearing the end of life such as becoming bed-bound or developing urinary and faecal incontinence. The Alzheimer's Society have helpful information about this area and other aspects of palliative care and end of life care on their website<sup>(12)</sup>.

Dementia is an important risk factor for hypoglycaemia and in such patients can simply present as uncharacteristic behaviour at times, which can easily be misinterpreted as declining mental status. Patients with dysphasia may find it difficult to explain hypoglycaemic episodes even if they recognise it in the first place. Regular monitoring of the blood glucose meter and discussions with carers should help highlight these episodes.

Another issue is the variability in nutritional intake and weight loss. As cognition declines and dementia progresses, patients have reduced appetite and nutritional intake. This will not only affect medication choice and dosing (especially insulin), but also increases the risks of hypoglycaemic episodes. A recent study found that, in patients with dementia, there was a higher risk of hypoglycaemic episodes when managed intensively.

## Cancer

Many individuals approaching the end of life will do so with, or because of, a cancer diagnosis. Management of cancer may include surgery, chemotherapy, radiotherapy, surveillance investigations and palliative interventions, all of which have implications for the management of pre-existing diabetes. Cancer can feature at any stage described within the Gold Standards Framework so strategies for glucose management will be influenced by prognosis and well-being, adapting as time passes. Simplification of therapy as well as intensification can have an emotional impact on individuals and carers so a planned, agreed joint approach reduces anxiety. Changes to diabetes care or targets if cancer care moves from curative to palliative can feel dismissive unless managed with sensitivity.

The aim remains maintenance of independence in self-care through evolving cancer treatment. Close relationships among clinical teams including diabetes specialists are to be encouraged as most factors that impact on glucose levels or other symptoms such as worsening of neuropathy are predictable. Weight loss, appetite and lifestyle changes are to be anticipated regardless of mode of intervention. Preparation for tests including starvation or bowel preparation is common and stressful for individuals using glucose lowering therapies. Mealtimes can also be disrupted by investigation or treatment schedules, including recurrent admissions or outpatient appointments. Chemotherapy regimens have become increasingly complex so the diabetes team may be entirely unfamiliar with these therapies, however they have to be involved in managing side effects such as vomiting or assisting in glucose control in neutropaenic sepsis. Other teams may have limited experience of insulin pumps and require clear advice on setting adjustments.



## Cancer (continued)

Changes in diabetes control can also be a sign of underlying malignant disease requiring a degree of suspicion among diabetes team members. In addition the acute presentation of new diabetes can also be a sign of cancer (e.g. pancreatic). Obesity is an independent risk factor for a variety of cancers. An excess of cancer diagnoses is seen in individuals at the phase of diabetes intervention with higher doses of insulin, however Metformin gives some cancer protection. Contact with different health workers can result in delays in recognition especially for individuals managed across clinical teams in different settings, using a variety of record systems. Unexplained variations in control should prompt further questioning for red flag symptoms whether systemic (e.g. weight loss, sweats, fatigue) or local (e.g. suspicious masses, cough, changing bowel habit, haematuria).

Surgery itself and increasing use of steroids in therapeutic regimes can result in new diagnoses of diabetes which can be overwhelming in an already difficult situation. Whether steroids are used in conjunction with chemotherapy, as an anti-emetic or as an appetite inducer, the impact on glucose can be managed with sulphonylurea or insulin. Early inclusion of the diabetes team can help with the practicalities and emotional impact of the diagnosis.

## Renal

Diabetes remains the commonest cause of end stage kidney disease in the UK; around 30% of individuals with renal failure have diabetic kidney disease<sup>(13)</sup>. Although the presence of diabetes confers additional risk for individuals by itself, the reality is that individuals with diabetes and kidney failure often have a range of co-existing illnesses (e.g. hypertension, ischaemic heart disease), putting them at high risk of a more rapid deterioration in health.

Optimising diabetic management in these individuals can be challenging as there is a fine balance in the management of glycaemic control in individuals with reduced appetite and altered clearance of medications as a result of reduced renal function or dialysis. As a result, uncertainty remains about the optimal glycaemic target for individuals with renal failure, including those on dialysis. However international guidelines recommend just moderate HbA1c targets 53 mmol/mol (>7%)<sup>(14)</sup> for individuals with advanced CKD who have significant co-morbidities, limited life-expectancy or a risk of hypoglycaemia.

The key, as with all individuals approaching end of life care, is to ensure good communication between the multi-professional team and the individual. This should include regular clinical review as individuals' circumstances are likely to change over relatively short periods.

➤ **Appendix 3: Renal**

## Key Features of Care for Vulnerable Groups with Diabetes at End of Life

A number of common features emerge that reflect the major challenges of managing vulnerable special populations at end of life. Four management areas require a vigilant attitude of all clinicians involved and these are:

- A. Recognition that vulnerability leads to difficulties in diabetes self-care and self-medication, poor adherence to treatment instructions, communication of an individual's needs particularly in those with cognitive impairment, a deterioration in glucose control, and need for carer and/or nursing input. Residency in a care home exacerbates these risks dramatically.
- B. An acceptance that the place of care may not always be at home or in agreement with the known wishes of a person entering the end of life phase (unless this is dealt with in an advance care plan) since the onset of severe frailty or dementia may influence the clinician's choice of best place of care. Diabetes management requirements should not influence choice of place of care.
- C. **Glucose Control and Glucose lowering medications** – the general principles that have been outlined in 'Management Goals in Key Clinical Areas' apply for both these areas. In general, the usual HbA1c target of 53-64 mmol/mol (7.0-8.0%) is appropriate but a HbA1c target up to 70 mmol/mol (8.5%) may be appropriate in those who are frail or demented. In those at end of life, the glycaemic target is predominantly to avoid symptomatic hyperglycaemia.
- D. **Nutrition** – despite the association of diabetes with obesity, each of the named vulnerable conditions/situations above can be associated with swallowing difficulties, weight loss, diminished nutritional status, vulnerability to infection, poor adherence to nutritional planning and increased needs for nutritional support.

# NUTRITION

## Nutrition

National guidance gives clear information on the need to provide fluids in the last days if it is the individuals wish<sup>(15)</sup>. It is acknowledged that clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may cause other problems such as fluid overload.

It is uncertain whether offering clinically assisted hydration prolongs life or if withdrawal of fluids hastens death. A therapeutic trial of clinical assisted hydration should be considered if the individual has distressing signs of dehydration such as thirst or delirium and oral hydration is not inadequate. In these circumstances there should be review of the individual for at least 12 hours assessing for symptom changes, signs of dehydration, and any evidence of harm or benefit. Reduce or stop clinically assisted hydration if there are signs of possible harm to the dying person, such as fluid overload, or if they no longer want fluids<sup>(15)</sup>.

## Individuals with problems swallowing or poor appetite

Changes in meal size or frequency can have a significant impact on glucose levels. In addition, individuals with diabetes may also 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 individuals. Insulin-treated individuals 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 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 individual'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 a solution for individuals not coping with tablets.

- Avoid long-acting sulphonylurea preparations (Glibenclamide, Gliclazide, Glipizide or Glimepiride) if small meals are being taken
- Repaglinide can be useful for individuals managing small regular meals with dose adjusted according to intake. Repaglinide should only be taken with food
- Low dose insulin may be the only option for individuals whose glucose levels are high despite a significantly reduced oral intake
- Individuals on insulin with poor intake will need lower doses
- Strict avoidance of added sugars is not necessary when food choices are already limited

## Enteral Feeding and Diabetes Treatment

Aims of the feed and diabetes treatment

- To provide adequate nutrition
- To keep safe (avoid very low blood glucose levels)
- To manage symptoms of high blood glucose

### Finding the right insulin for the feeding regimen

The content of the feed should be agreed following an assessment by a dietitian. It will include adequate vitamins, minerals, fats, proteins, carbohydrates and fluids, as well as the right number of calories to maintain an ideal weight.

However, in people with diabetes, the carbohydrate content of the feed may make the blood glucose rise too high. The kidneys respond to this by taking glucose from the blood and moving it into the urine, where it is excreted by the body. The loss of glucose in the urine means a loss of calories and therefore energy source.

Most diabetes tablets are not available in liquid form (the exception is Metformin). Tablets should not be crushed and inserted into the feeding tube as this may block the tube and also the medication may not work correctly. Therefore, if other diabetes medication is required to control blood glucose, insulin therapy is needed.

There are a number of different types of insulin which vary in how quickly and how long they last for. The type of insulin used will depend on the content, duration and frequency of the feeds. The insulin needs to work during the time that the feed is active (and when the glucose levels in the blood are rising). If there is a mis-match, the blood glucose may drop too low or rise too high. The table below gives some common feed and insulin regimens:

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**Prolonged feed (e.g. overnight):** Intermediate insulin is given at the start of the feed, or a mixture of intermediate and short-acting insulin is given at the start and half-way through the feed

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**Bolus feeds:** a short-acting insulin at the beginning of every feed (a long-acting insulin is also needed in people with type 1 diabetes)

---

**Continuous feed with regular or ad hoc meals:** an intermediate or long-acting insulin is given at the beginning of the feed, and a short-acting insulin is given with each meal or supplementary feed consumed

---

## Hypoglycaemia

In someone without diabetes, the right amount of insulin is produced by the body to keep the blood glucose levels steady, and never too low or too high. In someone with diabetes using insulin, the blood glucose may drop too low. If there is a mis-match between the insulin dose or type, and the carbohydrate content of the feed.

Other factors can increase the risk of hypoglycaemia with insulin therapy:

- Increased activity (e.g. physiotherapy, restlessness due to pain)
- Feeding tube is blocked or positioned incorrectly
- The carbohydrate content of the feed is reduced but the insulin dose or type is not adjusted
- Insulin is injected into muscle instead of fat. This results in the insulin working too quickly
- Stopping the feed
- Vomiting
- Malabsorption
- Insulin is not given at the correct time

### Signs and symptoms of low blood glucose less than 4 mmol/l although symptoms can occur at higher levels

- Shaking
- Sweating
- Pallor
- Confusion
- Drowsiness
- Coma

### Eating and its many benefits

Eating and food does not just provide nutrition. For example, it plays an important part in social interaction, and gives feelings of pleasure and enjoyment. People who are unable to eat normally and using enteral feeding miss out on these benefits.

Also, food plays an important role in the self-management of diabetes, and so enteral feeding may be associated with a feeling of loss of control, loss of choice and loss of enjoyment of eating. If communication problems are present as well, it is not surprising if low mood and depression sets in. Discussion with the GP and referral to counselling services in the community may be helpful. ([www.trend-uk](http://www.trend-uk))

## ADVANCE CARE PLANNING

For people with diabetes at end of life it is important that all are involved in effective and focused planning with their family and carers, and multidisciplinary care team to document their wishes relating to decisions about their future treatments. Such a plan is often triggered by a marked deterioration in the individual's functional status or the development of medical complications likely to lead to the individual entering a terminal phase (with less than 3 months to live) – however, effective care planning occurs when important decisions about future treatments or overall healthcare are taken at a much earlier stage.

Two important types of advance planning are usually recognised within the NHS: an advance decision (sometimes known as an advance decision to refuse treatment, an ADRT or a living will) and an Advance Statement.

### An Advance Decision

This represents a legally binding written decision an individual with mental capacity can make now to refuse a specific type of treatment at some time in the future. It requires both the individual and a witness to sign the document. It is helpful because it informs all those involved in the individual's care e.g. family, carers, health professionals, that the individual has a specific wish to refuse specific treatments in the future and this becomes essential if that individual loses the ability to communicate effectively. To be valid this document must state the words "even if my life is at risk". The treatment category must be named in the ADRT and it is wise that all relevant circumstances and situations where treatment should not be given are clearly indicated, e.g. cardiopulmonary resuscitation (CPR). A clinician should assist this process where appropriate.

A charity called **Compassion in Dying** has an advance decision form that individuals can complete online or in ink by hand. It is available at: <https://compassionindying.org.uk/choose-a-way-to-make-an-advance-decision-living-will/>

### An Advance Statement

An advance statement is a written statement that sets down the preferences, wishes, beliefs and values a mentally competent individual wishes to record about their future care. The plan should include instructions of who the individual and the family should contact if the anticipated emergency occurs. It is important that the plan is shared with all healthcare care professionals involved. Individuals should be advised to sign the statement although this is not absolutely necessary. It is sometimes seen as an alternative to an ADRT but should not be advised to be such as it is not restricted to a particular treatment but covers any aspect of future health or social care, e.g. ensuring that any religious or spiritual beliefs in that person's care are reflected adequately, or where an individual would like to be cared for such as at home or at a hospice. It provides a guide to anyone who might have to make decisions in the best interest of that individual who may have lost the capacity to make decisions or to communicate them. Whilst such a statement is not legally binding, it informs those who are involved in their care about their views and wishes with the hope that these will be respected.

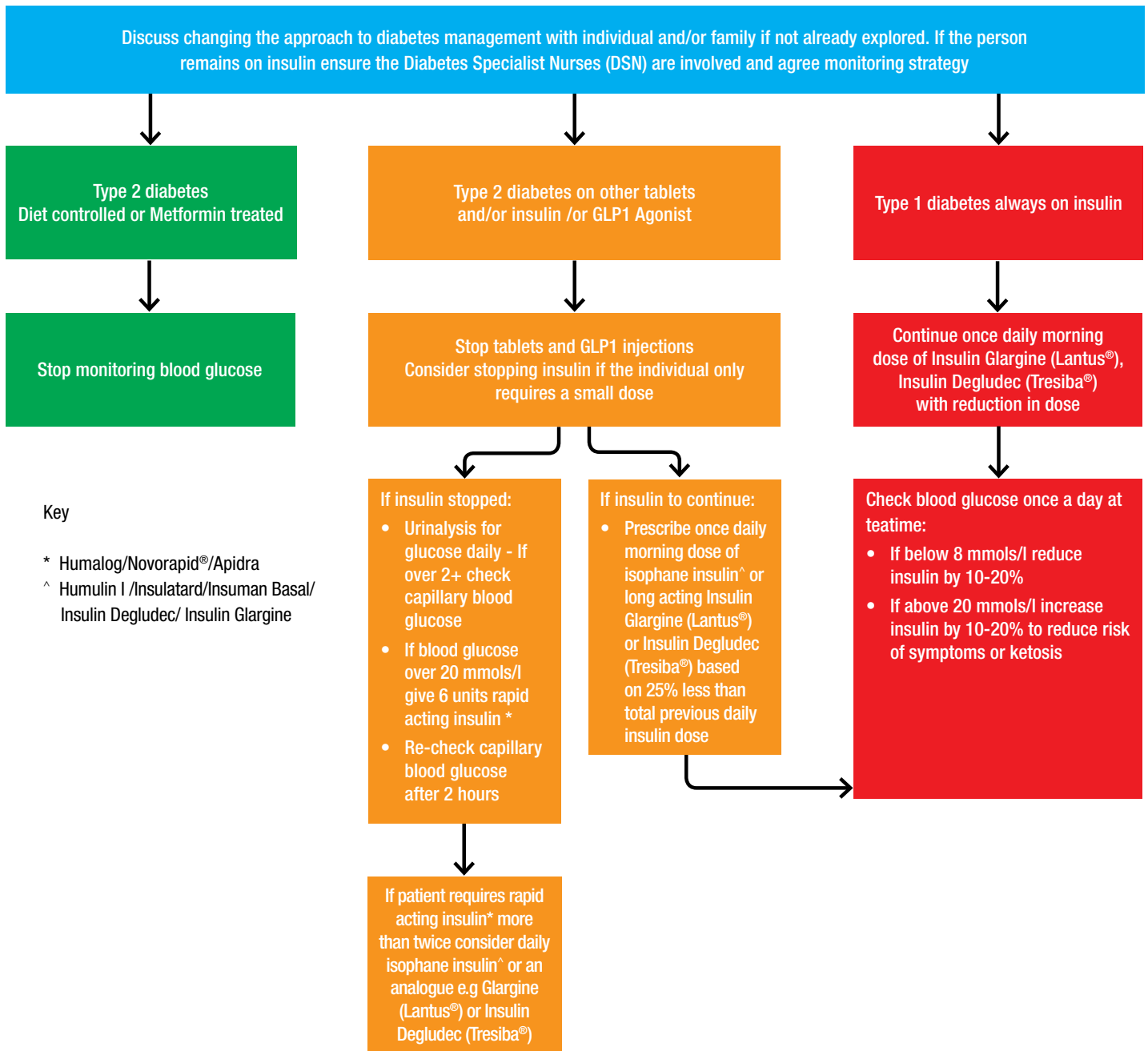
### Emergency Health Care Planning (EHCP)

An EHCP makes communication easier in the event of a healthcare emergency. Tackling an EHCP includes shared decision making and recording around expectations and capabilities of the individual and carers in the event of predictable situations or emergencies. The plan should include a list of regular and prn medications, and indications for any rescue medications left in the individual's home for emergency use. It could include plan for insulin adjustment or rescue doses of short acting insulin analogues.

Example documents and guidance is available on <http://www.cnne.org.uk/end-of-life-care---the-clinical-network/Decidingright> but local documents will also be available.

The **Dying Matters** website has information on talking about dying and how to let others know an individual's wishes. It is available at: <http://www.dyingmatters.org/overview/need-support>

Figure 1 - Algorithm for the last days of life



- 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.
- Flash glucose monitoring may be useful in these individuals to avoid finger prick testing

# STEROID THERAPY

## 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. Steroids can also cause “steroid induced” diabetes in those not previously diagnosed with the condition. The impact of a new “diabetes” diagnosis in those already living with a palliative diagnosis can be very difficult to cope with. 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). See Figure 2 on next page for managing individuals on once daily steroid.

JBDS ip Management of Hyperglycaemia and Steroid (Glucocorticoid) Therapy - [http://www.diabetologists-abcd.org.uk/JBDS/JBDS\\_IP\\_Steroids.pdf](http://www.diabetologists-abcd.org.uk/JBDS/JBDS_IP_Steroids.pdf)

If hypoglycaemia is a concern, once daily Insulin Glargine (Lantus®) or Insulin Degludec (Tresiba®) given in the morning may be a safer, especially for those new to insulin.

Early discussions with the Diabetes Specialist Team can assist in choosing the more appropriate steroid and blood glucose lowering treatment.

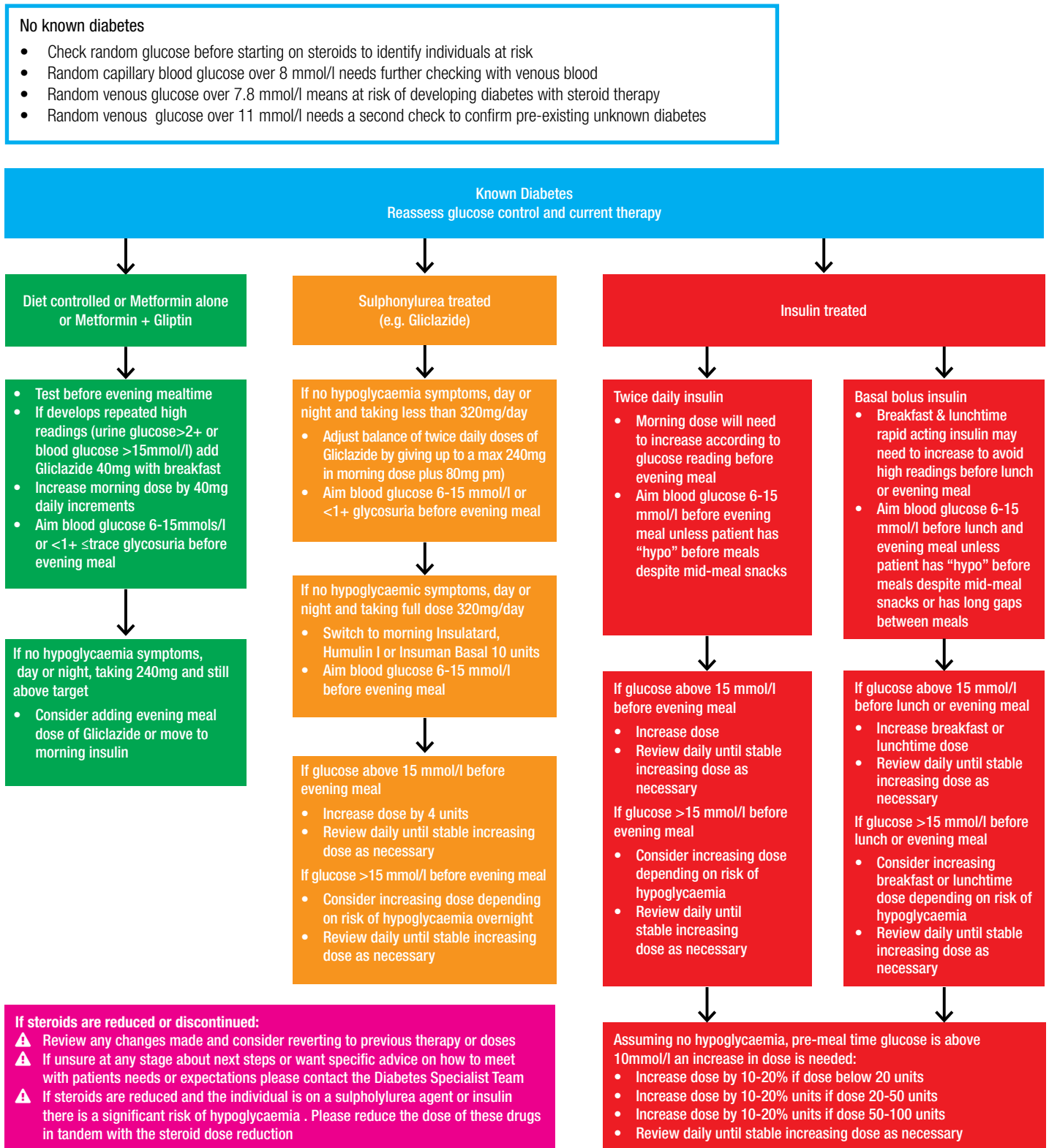
Short-term courses (less than 3 days) of steroids may only require closer monitoring but longer courses will require a review of glucose-lowering therapy and may result in a switch from oral agents to insulin. In this latter situation, an insulin regimen (e.g. Humulin I®/ Insulatard® or Insuman Basal®) given once daily should be considered.

Liaison with a community dietitian may assist in meal planning.





Figure 2 - Algorithm for Managing Glucose with Once Daily Steroid Therapy



# HYPOGLYCAEMIA

In a dying individual it is important to recognise signs and symptoms of hypoglycaemia and, treat appropriately, and you may need to stop hypo-inducing blood glucose lowering treatment. However, if the patient is in their preferred place of death and death is imminent it may be necessary to manage symptoms at home. Likewise if a hospital inpatient is hypoglycaemic despite on-going appropriate iv therapy it may be necessary to stop the active treatment of blood glucose lowering treatment and treat the patient symptomatically.

## Hypoglycaemia Management

Hypoglycaemia can be troublesome at any time in individuals 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 information may 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 preparations, sulphonylurea (e.g. Gliclazide, Glipizide, Glimpiride) and prandial regulator users (Nateglinide, Repaglinide). Individuals who are at particular high risk include those who also have one or more of the following:

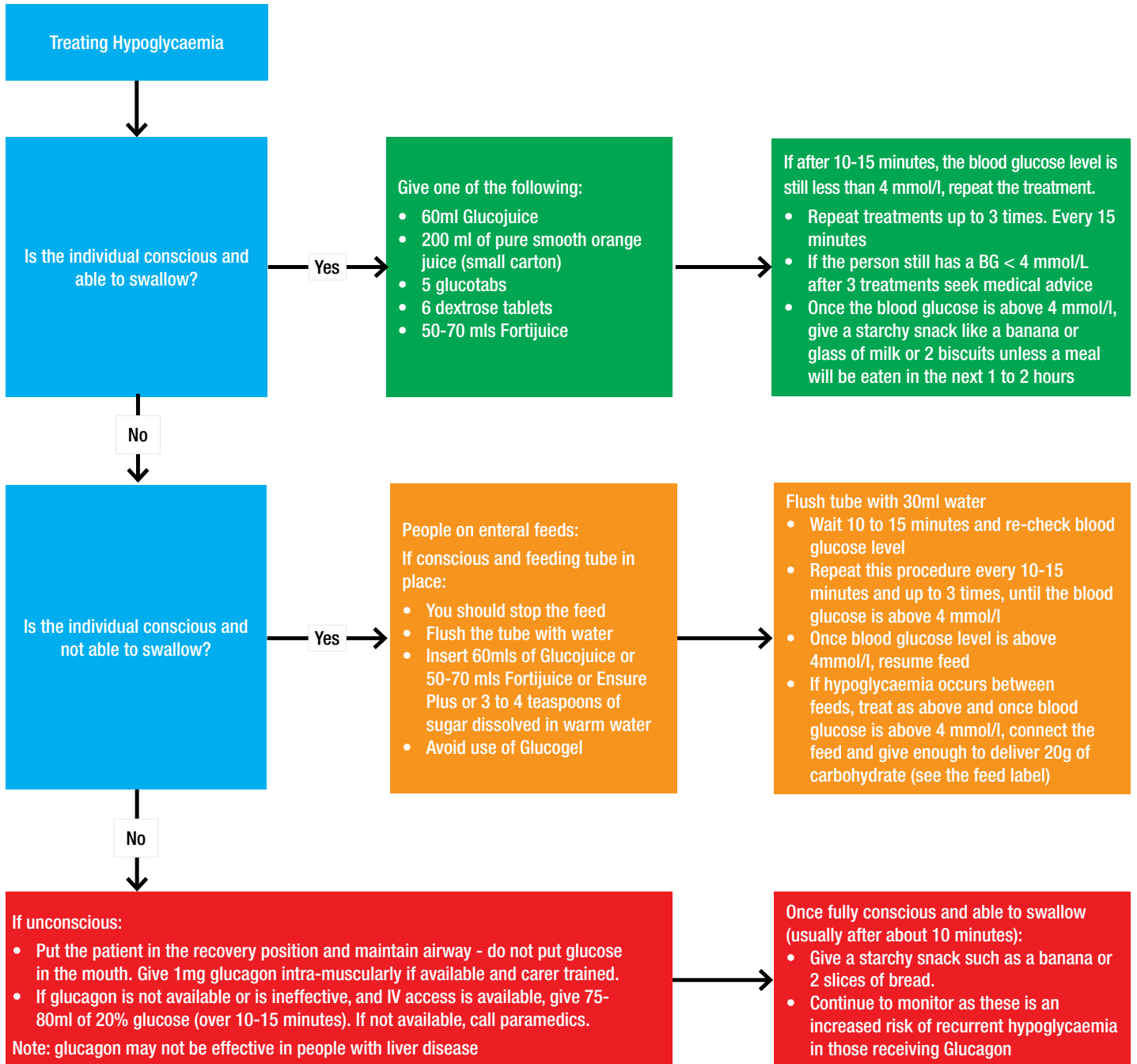
- Poor appetite/erratic eating pattern
- Weight loss
- Renal deterioration
- Liver impairment/ carcinoma
- Nausea and vomiting
- Previous gastrectomy
- Frailty
- Memory problems



### Identifying hypoglycaemia: signs and symptoms:

- > 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 individual is comatose that it is due to the end of life primary condition.

Figure 3 - Algorithm for 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

These sick day rules are for use in individuals who may be unwell as a result of the side effects of chemotherapy or have an inter current illness. 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
Keep on usual diabetes medication	Check blood glucose only to confirm symptoms of hyperglycaemia or hypoglycaemia
Sip sugar-free fluids regularly (aim for 100 ml per hour)	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
Offer frequent small portions of easily digested foods or fluids e.g. soup, ice cream, milky drinks	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
Observe for signs and symptoms of hyperglycaemia and dehydration	Glycaemic treatments may be discontinued if the individual is not eating and blood glucose level is less than 15mmol/l and individual is symptom-free
Only check capillary blood glucose to confirm hyperglycaemia: <ul style="list-style-type: none"> <li>• Aim to maintain blood glucose at 15 mmol/l or less</li> <li>• If blood glucose &gt; 15 mmol/L consider giving insulin</li> </ul>	
Stop SGLTs agents and Metformin in acute illness	

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 individual 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/fast acting insulin (e.g. Humulin S, NovoRapid, Apidra, Fiasp) 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 individual is vomiting, admit to hospital if the individual is cared for in the community setting, for intravenous insulin and rehydration see (please see sick day rules)	

➤ **Appendix 4:** Example of Sick-Day Management for End of Life Care Guidance for Healthcare Professionals Information Leaflet

## WITHDRAWAL OF TREATMENT



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

- When the individual with diabetes is entering the terminal phase of life
- Where frequent treatment-related hypoglycaemia is causing distress and significant management difficulties
- 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 are not the choice of the individual
- Where continued treatment with insulin poses an unacceptable risk of hypoglycaemia or where the benefits of stricter glucose control cannot be justified

Multiple factors may influence this process:

- Individual's wishes
- Dealing with concerns by family of a 'euthanasia' approach
- Presence of an Advance Directive
- Nasogastric feeding may be warranted for a brief spell close liaison with the individual, family and GP is warranted in this scenario

## COMPETENCIES AND WORKFORCE TRAINING

National organisations and published standards require that healthcare professionals providing care and support for people approaching end of life and their carers have the knowledge, skill and competencies needed to provide high quality care<sup>(15-18)</sup>.

It is recognised that healthcare professionals may lack core skills pertaining to end of life care. The General Medical Council (GMC) recommend that medical staff are familiar with relevant guidelines and developments that affect their work in providing care towards the end of life, and that they regularly take part in educational activities that maintain and develop competence and performance in this area<sup>(18)</sup>.

The Neuberger Report, stated that there should be condition-specific guidance and recommended that all clinicians should demonstrate proficiency in the care of the dying as part of their cycle of revalidation<sup>(19)</sup>. The Nursing and Midwifery Council provided a position statement<sup>(20)</sup> on the care of the dying in response to endorsement of a collaborative report provided by the Leadership Alliance<sup>(21)</sup>. This emphasised that all staff providing such care should have the skills and abilities to do so effectively and compassionately, and that it was the responsibility of an employing organisation to ensure that their workforce are competent and receive on-going professional development in this area.



Topics to be included in training should encompass:

- Assessment of Nutritional and Hydration States
- Importance of the person-centred care approach to the caring process which includes all aspects of an individual's life as well as symptom management
- The importance of assessment of pain, assessing impact of co-existing co-morbidities including frailty, communication, shared decision - making regarding medication and safe prescribing. This would also apply to diabetes medication and associated adverse effects including hypoglycaemia.
- Sensitive communication skills including empathy, recognising emotional response to stress and distress, discussing uncertainty, treatment limitations and withholding or discontinuation of treatment and preferred place of death.

Nursing competencies for care of people with diabetes in end of life care are already available<sup>(22)</sup>.

➤ **See Appendix 5 for Staff Competencies in End of Life Care**

## KEY ACTION POINTS



### RECOMMENDATIONS:

These clinical care recommendations emphasise the following:

- The need to balance benefits of diabetes interventions with prognosis/estimated time of life left
- As end of life approaches to minimise interventions and monitoring to keep the individual comfortable without compromising safety (i.e. avoid DKA or other metabolic complications)
- To involve individuals and family in decisions about diabetes management
- Diabetes management requirements can change quickly with steroid use, weight loss, liver or renal disease
- Involve the diabetes specialist nurse and dietitian especially if the individual has type 1 diabetes or type 2 treated with insulin

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### Useful Websites:

Ambitions for Palliative and End of Life Care  
[www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk)

End of Life Care Strategy  
[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_086277](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277)

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Scotland End of Life Care Strategy 2008  
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TREND-UK - Hypo, Illness, and Steroid Leaflets  
[www.trend-uk.org](http://www.trend-uk.org)

### Appendices

- **Appendix 1:** The GSF PIG 2016 - Proactive Identification Guidance
- **Appendix 2:** Insulin Tables
- **Appendix 3:** Prescribing Guidance in Patients with Renal Impairment
- **Appendix 4:** Example of Sick-Day Management for End of Life Care Guidance for Healthcare Professionals Information Leaflet
- **Appendix 5:** Staff Competencies in End of Life Care



# APPENDIX 1 - GOLD STANDARDS FRAMEWORK



## The Gold Standards Framework Proactive Identification Guidance (PIG)

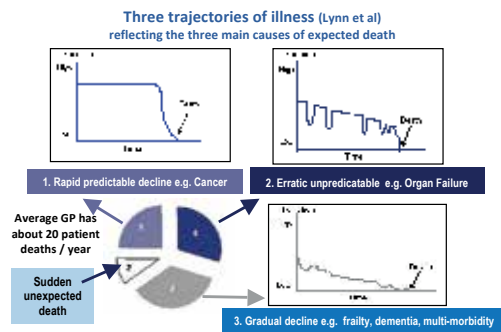


The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life leading to improved proactive person-centred care

GSF PIG 6th Edition Dec 2016 K Thomas, Julie Armstrong Wilson and GSF Team, National Gold Standards Framework Centre in End of Life Care <http://www.goldstandardsframework.org.uk> for more details see **GSF PIG**

### Proactive Identification Guidance – proactively identifying patients earlier.

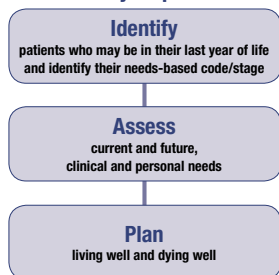
This updated 6th edition of the GSF PIG, renamed as Proactive Identification Guidance and formally known as Prognostic Indicator Guidance, aims to enable the earlier identification of people nearing the end of their life who may need additional supportive care. This includes people who are nearing the end of their life following the three main trajectories of illness for expected deaths – rapid predictable decline e.g. cancer, erratic decline e.g. organ failure and gradual decline e.g. frailty and dementia. Additional contributing factors when considering prediction of likely needs include current mental health, co-morbidities and social care provision.



### Why is it important to identify patients early?

Earlier identification of people who may be in their final stage of life leads to more proactive person-centred care. About 1% of the population die each year, with about 30% hospital patients and 80% of care homes residents in their last year of life. Most deaths can be anticipated though a minority are unexpected (estimated about 10%). Earlier recognition of decline leads to earlier anticipation of likely needs, better planning, fewer crisis hospital admissions and care tailored to peoples' wishes. This in turn results in better outcomes with more people living and dying in the place and manner of their choice. Once identified, people are included on a register and where available the locality/electronic register, triggering specific active supportive care, as used in all GSF programmes and in GSF cross boundary care sites.

#### The 3 key steps of GSF



PIG and GSF – Early proactive identification of patients is the crucial first step of GSF, used by many thousands of doctors and nurses in the community and hospitals. For more information on GSF, how it is used in practice to help identify patients early, assess needs and wishes through advance care planning discussions and plan care tailored to patient choices, see the GSF website.

### National Policy support for earlier identification.

#### General Medical Council – 2010

[www.gmc-uk.org/static/documents/content/End\\_of\\_life.pdf](http://www.gmc-uk.org/static/documents/content/End_of_life.pdf)

The GMC definition of End of Life Care; 'People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

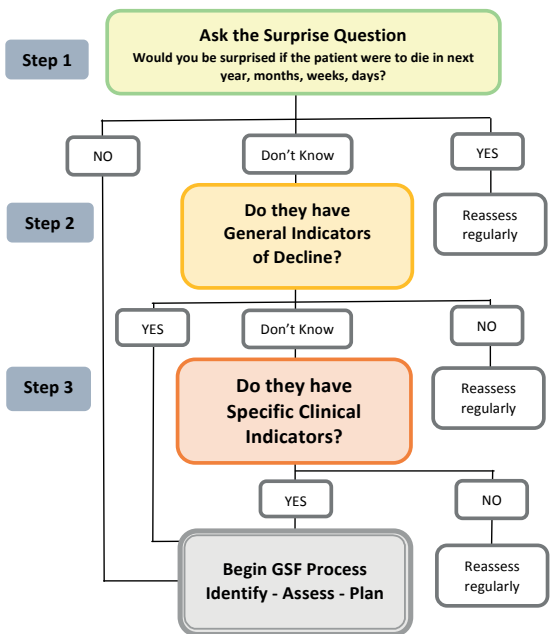
- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic events.'

#### NICE Guidance in End of life care 2011 Quality statement 1

<https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-1-Identification>

- 'Identification – People approaching the end of life are identified in a timely way.
- Systems – Evidence of local systems in place to document identification of people approaching the end of life.'

### Proactive Identification Guidance – GSF PIG Flow-chart



The GSF Proactive Identification Guidance (PIG) 2016 vs6 © The Gold Standards Framework Centre in End of Life Care  
For more information on the development of the GSF PIG, its use in practice, evidence base, applications and when referencing it, please refer to [www.goldstandardsframework.org.uk/PIG](http://www.goldstandardsframework.org.uk/PIG) For more details contact [info@gsfcentre.co.uk](mailto:info@gsfcentre.co.uk) 01743 291891

## The GSF PIG 2016 – Proactive Identification Guidance

### Step 1 The Surprise Question

For patients with advanced disease or progressive life limiting conditions, would you be surprised if the patient were to die in the next year, months, weeks, days? The answer to this question should be an intuitive one, pulling together a range of clinical, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

### Step 2 General indicators of decline and increasing needs?

- General physical decline, increasing dependence and need for support.
- Repeated unplanned hospital admissions.
- Advanced disease – unstable, deteriorating, complex symptom burden.
- Presence of significant multi-morbidities.
- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day and increasing dependence in most activities of daily living.
- Decreasing response to treatments, decreasing reversibility.
- Patient choice for no further active treatment and focus on quality of life.
- Progressive weight loss (>10%) in past six months.
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home.
- Serum albumin <25g/l.
- Considered eligible for DS1500 payment.

### Step 3 Specific Clinical Indicators related to 3 trajectories

#### 1. Cancer

- Deteriorating performance status and functional ability due to metastatic cancer, multi-morbidities or not amenable to treatment – if spending more than 50% of time in bed/lying down, prognosis estimated in months.
- Persistent symptoms despite optimal palliative oncology. More specific prognostic predictors for cancer are available, e.g. PPS.

#### 2. Organ Failure

##### Heart Disease

At least two of the indicators below:

- Patient for whom the surprise question is applicable.
- CHF NYHA Stage 3 or 4 with ongoing symptoms despite optimal HF therapy – shortness of breath at rest on minimal exertion.
- Repeated admissions with heart failure – 3 admissions in 6 months or a single admission aged over 75 (50% 1yr mortality).
- Difficult ongoing physical or psychological symptoms despite optimal tolerated therapy.
- Additional features include hyponatraemia <135mmol/l, high BP, declining renal function, anaemia, etc.

##### Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- Recurrent hospital admissions (at least 3 in last year due to COPD)
- MRC grade 4/5 – shortness of breath after 100 metres on level
- Disease assessed to be very severe (e.g. FEV1 <30% predicted), persistent symptoms despite optimal therapy, too unwell for surgery or pulm rehab.
- Fulfills long term oxygen therapy criteria (PaO2<7.3kPa).
- Required ITU/NIV during hospital admission.
- Other factors e.g., right heart failure, anorexia, cachexia, >6 weeks steroids in preceding 6 months, requires palliative medication for breathlessness still smoking.

##### Kidney Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least two of the indicators below:

- Patient for whom the surprise question is applicable.
- Repeated unplanned admissions (more than 3/year).
- Patients with poor tolerance of dialysis with change of modality.
- Patients choosing the 'no dialysis' option (conservative), dialysis withdrawal or not opting for dialysis if transplant has failed.
- Difficult physical or psychological symptoms that have not responded to specific treatments.
- Symptomatic Renal Failure in patients who have chosen not to dialyse – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

##### Liver Disease

Hepatocellular carcinoma.

Liver transplant contra indicated.

Advanced cirrhosis with complications including:

##### Liver Disease *continued*

- Refractory ascites
- Encephalopathy
- Other adverse factors including malnutrition, severe comorbidities, Hepatorenal syndrome
- Bacterial infection current bleeds, raised INR, hyponatraemia, unless they are a candidate for liver transplantation or amenable to treatment of underlying condition.

##### General Neurological Diseases

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Symptoms which are complex and too difficult to control.
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure.
- Speech problems: increasing difficulty in communications and progressive dysphasia.

##### Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments.
- Reduced independence, needs ADL help.
- The condition is less well controlled with increasing "off" periods.
- Dyskinesias, mobility problems and falls.
- Psychiatric signs (depression, anxiety, hallucinations, psychosis).
- Similar pattern to frailty – see below.

##### Motor Neurone Disease

- Marked rapid decline in physical status.
- First episode of aspirational pneumonia.
- Increased cognitive difficulties.
- Weight Loss.
- Significant complex symptoms and medical complications.
- Low vital capacity (below 70% predicted spirometry), or initiation of NIV.
- Mobility problems and falls.
- Communication difficulties.

##### Multiple Sclerosis

- Significant complex symptoms and medical complications.
- Dysphagia + poor nutritional status.
- Communication difficulties e.g., Dysarthria + fatigue.
- Cognitive impairment notably the onset of dementia.

### 3. Frailty, dementia, multi-morbidity

#### Frailty

For older people with complexity and multiple comorbidities, the surprise question must triangulate with a tier of indicators, e.g. through Comprehensive Geriatric Assessment (CGA).

- Multiple morbidities.
- Deteriorating performance score.
- Weakness, weight loss exhaustion.
- Slow Walking Speed – takes more than 5 seconds to walk 4 m.
- TUGT – time to stand up from chair, walk 3 m, turn and walk back.
- PRISMA – at least 3 of the following:

Aged over 85, Male, Any health problems that limit activity?, Do you need someone to help you on a regular basis?, Do you have health problems that cause require you to stay at home?, In case of need can you count on someone close to you?, Do you regularly use a stick, walker or wheelchair to get about?

#### Dementia

Identification of moderate/severe stage dementia using a validated staging tool e.g., Functional Assessment Staging has utility in identifying the final year of life in dementia. (BGS) Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score >3

Plus any of the following: Weight loss, Urinary tract Infection, Severe pressures sores – stage three or four, Recurrent fever, Reduced oral intake, Aspiration pneumonia. NB Advance Care Planning discussions should be started early at diagnosis.

#### Stroke

- Use of validated scale such as NIHSS recommended.
- Persistent vegetative, minimal conscious state or dense paralysis.
- Medical complications, or lack of improvement within 3 months of onset.
- Cognitive impairment / Post-stroke dementia.
- Other factors e.g. old age, male, heart disease, stroke sub-type, hyperglycaemia, dementia, renal failure.

# APPENDIX 2 - INSULIN

## DIABETES UPDATE

## INSULINS

Name	Manufacturer	Source	Delivery system	Taken	Onset, peak and duration (approximate hours)
<b>Rapid-acting</b>					
NovoRapid	Novo Nordisk	Analogue	Vial, cartridge, pre-filled pen	Just before / with / just after food	
Humalog	Lilly	Analogue	Vial, cartridge, pre-filled pen	Just before / with / just after food	
Apicla	Sanofi	Analogue	Vial, cartridge, pre-filled pen	Just before / with / just after food	
<b>Short-acting / neutral</b>					
Actrapid	Novo Nordisk	Human	Vial	30 mins before food	
Humulin S	Lilly	Human	Vial, cartridge	20-45 mins before food	
Hypurin Bovine Neutral	Wockhardt UK	Bovine	Vial, cartridge	30 mins before food	
Hypurin Porcine Neutral	Wockhardt UK	Porcine	Vial, cartridge	30 mins before food	
Insuman Rapid	Sanofi	Human	Cartridge	15-20 mins before food	
<b>Medium-acting</b>					
Insulatard	Novo Nordisk	Human	Vial, cartridge, pre-filled insulin doser	To be determined by the healthcare team	
Humulin I	Lilly	Human	Vial, cartridge, pre-filled pen	About 30 mins before food or bed	
Hypurin Bovine Isophane	Wockhardt UK	Bovine	Vial, cartridge	To be determined by the healthcare team	
Hypurin Porcine Isophane	Wockhardt UK	Porcine	Vial, cartridge	To be determined by the healthcare team	
Insuman Basal	Sanofi	Human	Vial, cartridge, pre-filled pen	45-60 mins before food	
<b>Mixed</b>					
Humulin M3	Lilly	Human	Vial, cartridge, pre-filled pen	20-45 mins before food	
Hypurin Porcine 30/70 Mix	Wockhardt UK	Porcine	Vial, cartridge	To be determined by the healthcare team	
Insuman Comb 15	Sanofi	Human	Cartridge	30-45 mins before food	
Insuman Comb 25	Sanofi	Human	Vial, cartridge, pre-filled pen	30-45 mins before food	
Insuman Comb 50	Sanofi	Human	Cartridge	20-30 mins before food	
Humalog Mix 25	Lilly	Analogue	Vial, cartridge, pre-filled pen	Just before / with / just after food	
Humalog Mix 50	Lilly	Analogue	Cartridge, pre-filled pen	Just before / with / just after food	
NovoMix 30	Novo Nordisk	Analogue	Cartridge, pre-filled pen	Just before / with / just after food	
<b>Long-acting</b>					
Hypurin Bovine Lente	Wockhardt UK	Bovine	Vial	To be determined by the healthcare team	
Hypurin Bovine PZI	Wockhardt UK	Bovine	Vial	To be determined by the healthcare team	
Lantus	Sanofi	Analogue	Vial, cartridge, pre-filled pen	Once a day, any time (at same time each day)	
Levemir	Novo Nordisk	Analogue	Cartridge, pre-filled pen, pre-filled insulin doser	Once or twice daily (at same time each day)	



Information supplied and checked by the manufacturers: Lilly 01256 315000, Novo Nordisk 0845 600 5055, Sanofi 08000 352525, Wockhardt UK 01975 651261

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## APPENDIX 3: PRESCRIBING GUIDANCE IN PATIENTS WITH RENAL IMPAIRMENT

### ➤ METFORMIN, SULPHONYLUREAS AND GLINIDES

Drug	Mild renal impairment; CKD stage 2; eGFR 60–89 mL/min/1.73m <sup>2</sup>	Moderate renal impairment; CKD stage 3; eGFR 30–59 mL/min/1.73m <sup>2</sup>	Severe renal impairment; CKD stage 4–5; eGFR <30 mL/min/1.73m <sup>2</sup>
Metformin	• Consider dose reduction in relation to declining renal function	• Review factors that may increase the risk of lactic acidosis before considering initiation	• Avoid use
Glibenclamide	• Use reduced dose and monitor	• Use reduced dose and monitor	• Avoid use
Gliclazide	• No dose adjustment	• No dose adjustment	• Avoid use
Glimepiride	• No dose adjustment	• No dose adjustment	• Avoid use
Glipizide	• Use conservative dose	• Use conservative dose	• Avoid use
Tolbutamide	• Start on lower dose with careful monitoring of BG levels	• Start on lower dose with careful monitoring of BG levels	• Avoid use
Nateglinide	• No dose adjustment	• May need to adjust dose if CrCl is 15–50 mL/min	• May need to adjust dose if CrCl is 15–50 mL/min
Repaglinide	• Titrate dose with caution	• Titrate dose with caution	• Titrate dose with caution

- BG=blood glucose; CKD=chronic kidney disease; eGFR=estimated glomerular filtration rate; SCr=serum creatinine.
- Information taken from relevant drug summaries of product characteristics, available at: [www.medicines.org.uk](http://www.medicines.org.uk) (accessed 26.06.2017)

### ➤ PIOGLITAZONE AND THE DPP-4 INHIBITORS

Drug	Mild renal impairment; CKD stage 2; eGFR 60–89 mL/min/1.73m <sup>2</sup>	Moderate renal impairment; CKD stage 3; eGFR 30–59 mL/min/1.73m <sup>2</sup>	Severe renal impairment; CKD stage 4–5; eGFR <30 mL/min/1.73m <sup>2</sup>
Pioglitazone	• No dose adjustment	• No dose adjustment	• No dose adjustment when CrCl >4 mL/min • Avoid use in dialysis patients
Alogliptin	• No dose adjustment if CrCl >50 mL/min	• Reduce dose to 12.5 mg OD if CrCl 30–50 mL/min	• Reduce dose to 6.25 mg OD (including patients with ESRD requiring haemodialysis)
Linagliptin	• No dose adjustment	• No dose adjustment	• No dose adjustment
Saxagliptin	• No dose adjustment if CrCl ≥50 mL/min	• Reduce dose to 2.5 mg OD when CrCl 30–50 mL/min	• Reduce dose to 2.5 mg OD • Not recommended in ESRD requiring haemodialysis
Sitagliptin	• No dose adjustment	• Reduce dose to 50 mg OD	• Reduce dose to 25 mg OD (including patients with ESRD requiring haemodialysis or peritoneal dialysis)
Vildagliptin	• No dose adjustment if CrCl ≥50 mL/min	• Reduce dose to 50 mg OD	• Reduce dose to 50 mg OD

- CKD=chronic kidney disease; CrCl=creatinine clearance; eGFR=estimated glomerular filtration rate; ESRD=end-stage renal disease; OD=once daily.
- Information taken from relevant drug summaries of product characteristics, available at: [www.medicines.org.uk](http://www.medicines.org.uk) (accessed 26.06.2017)

> SGLT-2 INHIBITORS

Drug	Mild renal impairment; CKD stage 2; eGFR 60–89 mL/min/1.73m <sup>2</sup>	Moderate renal impairment; CKD stage 3; eGFR 30–59 mL/min/1.73m <sup>2</sup>	Severe renal impairment; CKD stage 4–5; eGFR <30 mL/min/1.73m <sup>2</sup>
Canagliflozin	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>Do not initiate if eGFR &lt;60 mL/min/1.73m<sup>2</sup></li> <li>Dose adjustment to 100 mg OD when eGFR &lt;60 mL/min/1.73m<sup>2</sup> (persistently)</li> <li>Discontinue when eGFR &lt;45 mL/min/1.73m<sup>2</sup> (persistently)</li> </ul>	<ul style="list-style-type: none"> <li>Avoid use</li> </ul>
Dapagliflozin	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>Avoid use</li> </ul>	<ul style="list-style-type: none"> <li>Avoid use</li> </ul>
Empagliflozin	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>Do not initiate if eGFR &lt;60 mL/min/1.73m<sup>2</sup></li> <li>Dose adjustment to 10 mg OD when eGFR &lt;60 mL/min/1.73m<sup>2</sup> (persistently)</li> <li>Discontinue when eGFR &lt;45 mL/min/1.73m<sup>2</sup> (persistently)</li> </ul>	<ul style="list-style-type: none"> <li>Avoid use</li> </ul>

- CKD=chronic kidney disease; CrCl=creatinine clearance; eGFR=estimated glomerular filtration rate; OD=once daily; SGLT-2=sodium-glucose cotransporter 2.
- Information taken from relevant drug summaries of product characteristics, available at: [www.medicines.org.uk](http://www.medicines.org.uk) (accessed 26.06.2017)

> GLP-1 RECEPTOR AGONISTS

Drug	Mild renal impairment; CKD stage 2; eGFR 60–89 mL/min/1.73m <sup>2</sup>	Moderate renal impairment; CKD stage 3; eGFR 30–59 mL/min/1.73m <sup>2</sup>	Severe renal impairment; CKD stage 4–5; eGFR <30 mL/min/1.73m <sup>2</sup>
Albiglutide	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>Avoid use</li> </ul>
Dulaglutide	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>Avoid use</li> </ul>
Exenatide twice daily (BD)	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>No dose adjustment if CrCl ≥50 mL/min</li> <li>Escalate dose from 5 µg to 10 µg with caution when CrCl 30–50 mL/min</li> </ul>	<ul style="list-style-type: none"> <li>Avoid use</li> </ul>
Exenatide once weekly (QW)	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>No dose adjustment if CrCl ≥50 mL/min</li> <li>Avoid use if CrCl &lt;50 mL/min</li> </ul>	<ul style="list-style-type: none"> <li>Avoid use</li> </ul>
Liraglutide	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>No dose adjustment if CrCl &gt;15 mL/min</li> <li>Avoid use if CrCl &lt;15 mL</li> </ul>
Lixisenatide	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>No dose adjustment</li> </ul>	<ul style="list-style-type: none"> <li>Avoid use</li> </ul>

- BD=twice daily; CKD=chronic kidney disease; CrCl=creatinine clearance; eGFR=estimated glomerular filtration rate; GLP-1=glucagon-like peptide-1; OD=once daily; QW=once weekly.
- Information taken from relevant drug summaries of product characteristics, available at: [www.medicines.org.uk](http://www.medicines.org.uk) (accessed 26.06.2017)


# APPENDIX 4 - SICK DAY MANAGEMENT

## 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 the last year of 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	2. Patients with Type 2 diabetes on a sulphonylurea, prandial regulator and/or insulin
<ul style="list-style-type: none"> <li>• Encourage the individual to take small sips of fluid regularly. (aim for 100ml per hour)</li> <li>• Offer frequent small portions of easily digested foods or fluids e.g. soup, ice cream, milky drinks</li> <li>• Observe for signs and symptoms of hyperglycaemia and dehydration</li> <li>• Only check capillary blood glucose to confirm hyperglycaemia: aim to maintain blood glucose at 15mmol/l or less</li> <li>• Consider stopping Metformin and or an SGLT2 if the patient has sickness/diarrhoea</li> </ul> 	<ul style="list-style-type: none"> <li>• Check blood glucose only to confirm symptoms of hyperglycaemia or hypoglycaemia</li> <li>• 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</li> <li>• Consider increasing diabetes medications (if blood glucose levels above 15mmol/l) or reducing diabetes medication (if blood glucose levels less than 6mmol/l)</li> <li>• 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</li> </ul>

#### Type 1 Diabetes: Specific Advice

Patients with Type1 Diabetes on insulin treatment appropriate measures include:
<ul style="list-style-type: none"> <li>• Encourage the patient to sip sugar-free fluids regularly (aim for 100ml per hour)</li> <li>• If unable to eat usual meals, offer frequent small portions of easily digested foods or fluids e.g. soup, ice cream, milky drinks</li> <li>• Test for urine or blood ketones if patient has symptoms of hyperglycaemia and dehydration</li> <li>• 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 fast short-acting insulin (e.g. Actrapid, Apidra, Fiasp, Humulin S NovoRapid) every 2 hours if ++ or greater on urine ketone strip or greater than 1.5mmol on blood ketone test. *</li> <li>• If ketone levels do not improve, and the patient is vomiting, admit to hospital for intravenous insulin and rehydration</li> </ul> 



\* 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:

- The individuals 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. Where frequent treatment-related hypoglycaemia is causing distress and significant management difficulties
2. Where the benefits of stricter glucose control cannot be justified
3. Where the tablet burden and side effects of blood pressure tablets and lipid lowering therapy outweigh any long-term benefit
4. Where continued food or fluids is not the choice of the patient

### Treating hypoglycaemia

If patient conscious and able to swallow give one of the following:

200ml of pure smooth orange juice

60ml Glucojuice, 50-70ml Fortijuice or Ensure plus

Once blood glucose is  $>4\text{mmol/l}$  give a starchy snack

If patient conscious and unable to swallow, patients on PEG feeds:

Stop feed flush the tube then give 60ml of Glucojuice

60ml Glucojuice, 50-70ml Fortijuice or Ensure plus

Repeat procedure every 10-15 mins until blood glucose  $>4\text{mmol/l}$  and resume feed

**Always seek advice from the Diabetes Specialist Team**

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[www.diabetes.org.uk](http://www.diabetes.org.uk)

Design by Shehnaz Jamal: University Hospitals of Leicester [www.leicestershirediabetes.org.uk](http://www.leicestershirediabetes.org.uk)

Produced in cooperation with:



Association of British Clinical Diabetologists



Diabetes Frail



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# APPENDIX 5 - STAFF COMPETENCIES

## Competency statements

### 6.20. END-OF-LIFE CARE

To care for someone with diabetes at end of life you should be able to:	
<b>1. Unregistered practitioner</b>	<ul style="list-style-type: none"> <li>Undertake blood glucose monitoring and care as requested by registered nurse.</li> <li>Document and report blood glucose monitoring results according to local guidelines and protocols.</li> <li>Be aware of policies relating to end-of-life care and diabetes.</li> <li>Be aware of signs and symptoms that may indicate hypoglycaemia or hyperglycaemia.</li> </ul>
<b>2. Competent nurse</b>	<p>As 1, and:</p> <ul style="list-style-type: none"> <li>Assess the person's needs and ensure they are pain free, adequately hydrated and symptom free from their diabetes.</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>Demonstrate knowledge of appropriate blood glucose targets (e.g. 6–15 mmol/L) to avoid hypoglycaemia and hyperglycaemia.</li> <li>Be aware that glucocorticoid steroids may cause diabetes, which may require insulin treatment. Steroids can 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 and DKA or HHS.</li> <li>Be aware that people with type 1 diabetes must remain on insulin therapy during the last days of life.</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 that individual's eating pattern.</li> <li>Be aware that, where possible, diabetes treatment plans and medication changes must be discussed with the patient, relatives or carers.</li> </ul>
<b>3. Experienced or proficient nurse</b>	<p>As 2, and:</p> <ul style="list-style-type: none"> <li>Initiate and develop personalised care plans in collaboration with the person with diabetes and their carers/family.</li> <li>Describe indications for the initiation or discontinuation of blood glucose-lowering agents in agreement with the person with diabetes and their carers.</li> <li>Give advice on blood glucose monitoring and, if required, the appropriate frequency of monitoring in agreement with the person and carers.</li> <li>Recognise when treatment needs to be adjusted.</li> </ul>
<b>4. Senior practitioner or expert nurse</b>	<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 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> </ul>
<b>5. Consultant nurse</b>	<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 collections 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 them.</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 patients at end of life, the diabetes population as a whole and the diabetes service.</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 MDT care across service boundaries.</li> <li>Influence national policy concerning appropriate management of someone with diabetes at 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>

See: *End of Life Diabetes Care: Clinical Care Recommendations* ([www.diabetes.org.uk](http://www.diabetes.org.uk))









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