



For Healthcare Professionals:

# END OF LIFE GUIDANCE FOR DIABETES CARE

Endorsed by:

November 2021

**DIABETES UK**  
KNOW DIABETES. FIGHT DIABETES.



# CONTENTS

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Welcome and statement	Page 3
Foreword	Page 4
Steering Group	Page 5
Background	Page 6
Medication	Page 10
Nutrition	Page 18
Advance care planning	Page 20
Steroid therapy	Page 22
Hypoglycaemia	Page 24
Sick-day management	Page 26
Withdrawal of treatment	Page 27
Competencies and workforce training	Page 27
Summary	Page 28
Appendices	Page 29
Useful resources	Page 34
References	Page 35

# WELCOME AND STATEMENT

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End of life care in diabetes continues to be under investigated and there is a dearth of guidelines, recommendations, and research into this topic. Caring for people with diabetes as they approach the last year, month and days of life often falls to non-diabetes specialist healthcare professionals, so it is important that clear clinical recommendations are accessible to promote good quality care.

Throughout an individual's life span with diabetes there is a real focus on meeting clinical targets and avoiding long term micro and macrovascular complications. It is understandable that in the last year of life the relaxation of targets can cause some concern and distress to both the person living with diabetes, their family or carers. The multiplicity of insulin and non-insulin therapies available can make end of life care complicated so it is important that information relating to these medications and possible withdrawal of diabetes therapies, in some cases, is easy to access.

The recommendations are updated regularly and this is the fourth edition. We are delighted to carry on with the excellent work undertaken initially by Diabetes UK in the development of the original document, and thank the charity for their support in enabling this document to be updated

## **June James**

University Hospitals of Leicester and Co Chair Trend Diabetes

## **Debbie Hicks**

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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**



# FOREWORD

People with diabetes who are at the end of life have a specific 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 provides an update to the excellent resources produced by Diabetes UK since 2013<sup>1</sup>. It 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. A holistic approach addressing both the clinical aspects of care, and psychological and clinical challenges when caring for individuals living with diabetes is important and this is no less valuable in the last year of life<sup>1</sup>.

**Over half a million people died in the United Kingdom<sup>2</sup> in 2017 and, in the same year, 117,000 of these individuals had diabetes**

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<sup>3</sup>. 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. Most are attributed to cardiovascular disease including heart failure, chronic kidney disease, dementia, cancers.

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 manage 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 also applies to people dying with diabetes. Healthcare professionals need to be trained and competent to care for this population, therefore, an additional section on training and education of the healthcare workforce is included<sup>1</sup>.

This updated guidance summarises the major clinical problems that individuals with diabetes at the end of life experience and how these are best managed. 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, have dementia, or residing in a care home is given. This update also provides new recommendations relating to those with:

- Cancer
- End stage renal failure;
- People in the last days of life due to COVID 19.

Information on glucose lowering therapies including the newer insulin analogues is updated, and advanced care directives have been revised.

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.

## **Prof Alan Sinclair**

Foundation for Diabetes Research in Older People, Diabetes,  
Diabetes Frail

# STEERING GROUP

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## Acknowledgements

We would like to acknowledge the work of the original steering group from 2013: Jill Hill, Jean MacLeod, Elizabeth Kendrick and Angus Forbes and of the 2021 Trend Diabetes Committee, Erica Richardson, Liz Houghton, Julie Lewis, Lisa King, Sam Calder, and Debbie Voigt.

The working party would like to thank Diabetes UK for their encouragement and generous support in the development of this guidance.

## About Trend Diabetes

TREND-UK was a working group of diabetes nurses with different skills and backgrounds, set up in 2009 in response to a request for a collective voice that represented all diabetes nursing groups. The original founding co-chairs of TREND-UK were experienced Nurse Consultants, working in a variety of settings and who were closely involved with other organisations representing nurses and other healthcare professionals working in diabetes.

This original group has now evolved into Trend Diabetes to reflect their work with other countries as well as the UK. Trend Diabetes produces a number of resources for healthcare professionals and people living with diabetes. These are available at [www.trenddiabetes.online](http://www.trenddiabetes.online). Access to these resources is free of charge to anyone registering as a member of Trend Diabetes.

# BACKGROUND



**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:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions from which they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events<sup>4</sup>

## Early Identification

Early identification of people who are likely to be in their last year(s) of life is important. This allows the opportunity for important conversations to take place between the person and those important to them. It also allows open and honest conversations about what matters to the person, and opportunity for them to express their views and priorities about future care. These conversations may be initiated by the person, those important to them or their clinicians in any care setting.

The Gold Standards Framework Proactive Identification Guidance<sup>5</sup> and the Supportive and Palliative Care Indicators Tool (SPICT)<sup>6</sup> offer suggestions that may help the clinician to recognise that the individual's condition is beginning to progress or deteriorate, and to initiate discussions about personalised care and support planning, both for now and for the future.

**1** See Appendix 1 for Proactive Identification Guidance and Appendix 2 for SPICT.

The following are general indicators of decline, including:

- Decreasing activity – functional performance status, declining and limited self-care, spending at least half the day in the chair or in bed, increasing dependence in most activities of daily living
- Co-morbidity and multi-morbidity
- General physical decline and increasing need for support
- Advanced disease – unstable, deteriorating, complex symptom burden
- Diminishing response to treatment
- Decreasing reversibility
- Individual choice to discontinue disease-specific treatments, e.g. renal replacement therapy
- Progressive weight loss over the past 6 months or so
- Recurrent unplanned or crisis admissions
- Significant event, e.g. serious fall, bereavement, transfer to nursing home

#### 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 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)

**i See Appendix 1 for Proactive Identification Guidance and Appendix 2 for SPICT.**

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 when a person is approaching 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>7</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<sup>1</sup>

## 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<sup>1</sup>

## 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<sup>1</sup>.

### Other Medication

Once it has been recognised that the person is approaching the end of life 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'.





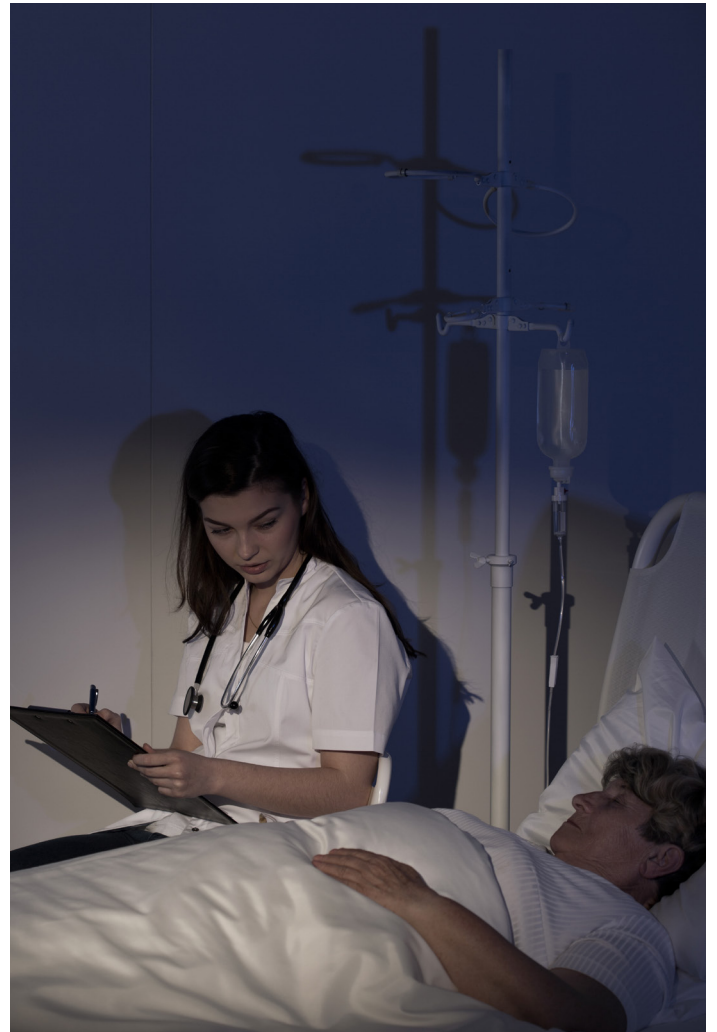
## De-Intensification of Therapies

It is inevitable that the therapeutic value of some prescribed medicines at end of life can be questioned and in particular as burden of taking multiple medication can be troublesome to the individual. Any decisions to reduce or withdraw part of the medicines load is usually based on clinical common sense or best practice rather than sound evidence to support these decisions. The process of de-intensifying therapy should be proactive and based on the likely benefits or not of continuing with the specific treatment versus the risk of harm from adverse drug effects and their consequences such as an hypoglycaemic episode causing a fall. Of course, withdrawing therapy of any kind raises ethical concerns and it is important that agreement is sought between clinicians involved and the person at end of life and his/her family. This should come only after a full explanation is provided by the clinician and the reasoning involved. A recording in the medical notes of the discussion and agreed plan of action is essential. This can be a difficult and emotionally challenging time and guidance is available from the General Medical Council in this area which is available at: Treatment and care towards the end of life - GMC (gmc-uk.org)<sup>4</sup>.

Whilst insulin should be maintained in those with type 1 diabetes. A shift to a simpler regimen such as once daily basal insulin to reduce the risk of diabetic ketoacidosis. The condition cause severe hyperglycaemia and dehydration so should be avoided wherever possible. In those on insulin with type 2 diabetes, efforts should be made to withdraw insulin completely whilst again ensuring there is no significant deterioration in glucose control. For those on other glucose-lowering therapy, there should be a monitored but active process of reducing or withdrawing treatments such as Glucagon-like peptide-1 receptor agonists (GLP-1 RAs) because of their adverse effects on appetite and associated weight loss and/or Sodium-glucose co-transporter-2 (SGLT2) inhibitors because of their adverse effects on fluid balance and the risk of urogenital infections. Lipid-lowering agents such as statins can also be considered for withdrawal because of unlikely benefits and the reduction of adverse effects such as muscle pain. Studies have shown that de-intensification in older adults with diabetes, particularly those with frailty, can be achieved without safety being unduly compromised and with little effect on HbA1c levels<sup>7,8</sup>.

## Palliative Care Drugs

The use of palliative care drugs, particularly for the treatment of pain and distress, should be managed by a specialist palliative care service whose quality and service delivery can be provided according to NICE guidance, QS 13 End of life care for adults<sup>9</sup> and NG 142<sup>10</sup>. Common classes of drugs used include analgesics for background and breakthrough pain, anti-secretory drugs, and sedatives and relaxants for agitated behaviour. An 'anticipated' approach to medicines prescribing in the terminal phase of life is recommended.



# 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<sup>5</sup>)** 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:

<b>A. Blue: "All" from diagnosis stable with year plus prognosis</b>	<b>B. Green: "Benefits" unstable / advanced disease - months prognosis</b>
<b>C. Yellow: "Continuing care" deteriorating weeks prognosis</b>	<b>D. Red: "Terminal care" - days prognosis</b>

### 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 during their lifetime 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**

<b>Metformin</b> Standard Metformin or Glucophage SR	<b>Sulphonylureas</b> Gliclazide / Glipizide / Glimepiride / Repaglinide	<b>Pioglitazone</b>	<b>Gliptins</b> Alogliptin, Linagliptin, Saxagliptin, Sitagliptin	<b>GLP-1 RAs</b> Exenatide or Liraglutide, Lixisenatide, Semaglutide, Bydureon, Rybelsus and Dulaglutide	<b>SGLT2 inhibitors</b> Dapagliflozin, Empagliflozin, Ertugliflozin and Canagliflozin
<b>Risk of hypoglycaemia with non insulin therapies when used as mono therapy</b>					
✘ No Risk	✔ Moderate Risk	✘ No Risk	✔ Low risk	✘ No risk	✔ Low risk
<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	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/L/1.73m <sup>2</sup>	Review dose if renal or liver function deteriorates and consider a switch to Tolbutamide	requires review and should be only prescribed if benefits can clearly be identified	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

## 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 held 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. Flash Glucose monitoring may be used as a means of monitoring without the need for capillary blood glucose testing.

**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

### 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 individuals 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 people who have hypoglycaemia unawareness. Individuals 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. Contact with the specialist diabetes team should be made to determine the dose of insulin to be given. 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 analogue long acting insulin 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: "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 21) , 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.

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. It is therefore helpful to encourage people to consider advance or future care planning well ahead of time so that they can make known their wishes and priorities to guide decision making if they become unable to participate fully.

## Care Home residents

Residents with diabetes have a high prevalence of associated medical co-morbidity, dementia, frailty and disability<sup>11</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>12</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>13</sup>. Diabetes care in care home settings may be suboptimal and the provision of high quality standards in end of life diabetes care may be poor it requires urgent action to address these shortfalls<sup>14</sup>.

## Frailty

Diabetes is independently associated with frailty and 40% or more people with diabetes aged 80 years are frail<sup>14</sup>. The presence of frailty increases the risk of reduced mobility, functional decline and decreased survival<sup>17,12</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>13</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 particularly at the early phase of the end of life scenario since later in the scenario, especially if moderate to severe frailty is present, proactive withdrawal of medicines becomes more important and palliative care may become a priority. Of course, the presence of frailty adds to the inevitable decline and earlier demise of the person at end of life, but may assist the clinician in care planning.

Screening for frailty should impose a minimum of health professional time and not require the individual at end of life to be engaged in procedures of any kind. The FRAIL test developed in both Europe and the United States has now been extensively validated across the globe. It is a 5-item 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. Scores are 1 – 5 where scores 3-5 indicate varying degrees of frailty with 5 being the more severe form. The Clinical Frailty Scale is an alternative visual questionnaire which allows the health professional to assign a level of frailty according to the descriptions on the questionnaire graded as levels 1-9. Levels 5-8 indicate mild, moderate, severe, and very severely frail, whilst level 9 indicates someone who is described as terminally ill. A detailed account of the above assessment tools and others used in frailty can be found at: <https://www.england.nhs.uk/ourwork/clinical-policy/older-people/frailty/efi/#is-this-extra-work-for-general-practice>

## Dementia

Diabetes increases the risk of cognitive impairment in someone living with dementia<sup>15</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. Declining HbA1C without change in therapy may be a signal of deterioration.

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<sup>16</sup>. 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>17</sup>.

Dementia is an important risk factor for hypoglycaemia and in such individuals can simply present as uncharacteristic behaviour at times, which can easily be misinterpreted as declining mental status. People 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 and discussions with carers should help highlight these episodes.

Variability in nutritional intake and weight loss may be problematic. As cognition declines and dementia progresses, these individuals will 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<sup>14,15</sup>.

## Cancer

Individuals with cancer are at an increased risk of developing new onset DM or hyperglycaemia, independent of an underlying diagnosis of diabetes, as well as challenging control of their pre-existing DM. It is estimated that 20% of people with cancer have a pre-existing diagnosis of diabetes<sup>18</sup>.

Changes in stable glucose management can be a sign of underlying malignant disease requiring a degree of suspicion among diabetes team members<sup>19</sup>. The acute presentation of new diabetes maybe be a sign of cancer (e.g. pancreatic). Obesity is an independent risk factor for a variety of cancers<sup>20</sup>.

Cancer diagnoses can be found in individuals at the phase of diabetes intervention with higher doses of insulin. Contact with different HCPs can result in delays in recognition especially for individuals managed across clinical teams in different settings, using a variety of record systems. It is important the specific pathways are developed to enable consistency and access to care for people living with both conditions. Unexplained variations in blood glucose level 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).

There is an increased risk of diabetic ketoacidosis in people with both diabetes and cancer, it is important that sick day advice is given and a hospital admission avoided if clinically possible<sup>21</sup>.

Many individuals approaching the end of life will do so with, or because of, a cancer diagnosis. Management of cancer may include surgery, chemotherapy, immunotherapy, supraphysiological doses of steroids, radiotherapy, surveillance investigations, palliative interventions, and those without a diagnosis of diabetes all of which have implications for the management of pre-existing diabetes.

Cancer can feature at any stage described within the Gold Standards Framework<sup>5</sup> 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 and/or enteral feeds 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, steroid induced hyperglycemia or assisting in glucose management in neutropenic sepsis. Other teams may have limited experience of insulin pumps and require clear advice on setting adjustments.

The use of diabetes technology is increasingly being used by people with diabetes and this can be unfamiliar to other teams, specialist advice maybe necessary to support the safe ongoing use of technology, sometimes a conversation back to pen devices may be considered a safer option for those who are compromised and unable to self manage.



## Cancer and nutrition

Chemotherapy can cause nausea and vomiting and, in some cases, there can also be a loss of taste in some individuals. Eating is a social activity; it helps people to feel better. When individuals are unable to join with others in this part of life, it can be of great concern to that person, and their carers<sup>22</sup>. Appetite loss, poor nutrition, changes in portion sizes, long gaps between eating and significant weight loss impacts on glycaemic management<sup>23</sup>. In these instances, calorie dense food such as chocolate can be encouraged along with smaller meals and little or no restriction in those foods with added sugars. Some people may will prefer cold meals if they are nauseated. If swallowing is difficult, and if the taking of oral blood glucose treatments troublesome; repaglinide, a very short acting medication can be used in those with type 2 diabetes or alternatively low dose insulin in people with type 1 and in type 2 diabetes can be considered<sup>24</sup>. Food supplements which may contain high levels of glucose may sometimes be the only nutrition that can be tolerated. If used, a medication review needs to take place as diabetes treatments may need revision.

Surgery itself and increasing use of steroids in therapeutic regimens 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. In individuals with pancreatic cancer the use of pancreatic enzyme Replacement therapy may be required.

## 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>25</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<sup>26</sup>. These individuals are at increased risk of foot ulceration; foot checks are needed regularly and foot protection devices should be used.

Optimising diabetes management in these individuals can be challenging as there is a fine balance in the management of glycaemic levels 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 53-64 mmol/mol (7-8%)<sup>26</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.

## COVID 19 induced hyperglycaemia and mortality

The World Health Organisation in March 2020 confirmed that COVID 19 was a pandemic infection. At the time the pandemic had claimed over 2 million people lives<sup>26,27</sup>.



Separate end of life care guidance relating to end of life care in people with COVID 19 has been developed by different organisations in the UK<sup>28,29</sup>; these focus on symptom relief and the need for a holistic approach to care but do not include diabetes management.

The Royal College of GPs issued guidance through a resource hub which included the need to have a conversation and initiating advance care planning (ACP) with the dying and their families before the people become less capable of expressing their preferences for treatment<sup>30</sup>.

The COVID 19 pandemic has had a considerable detrimental impact on the fate of care home residents who in the presence of diabetes may be particularly vulnerable<sup>31</sup>. It has demonstrated many shortfalls in care delivery within these settings because of staff shortages and lack of staff training and sometimes inadequate facilities, but also shown that care staff can rise to the challenge of the pandemic with great commitment and can provide end of life care. Staff have coped with complex medical situations and will need ongoing training in management of chronic disease including diabetes at the end of life if working in 24 hour care settings. Proactive engagement with families and with the local specialist teams can help in managing pre-existing diabetes in their residents.



## 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 Management 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 have dementia. 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

National guidance gives clear information on the need to provide fluids in the last days if it is the individuals wish. 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>32</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 sulphonylurea preparations (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 and can lead to distress

## 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 then insulin therapy is needed<sup>32</sup>.

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 mismatch, 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<sup>33</sup>

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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)

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**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

---

**Changes in the feeding regimen** require a review of the insulin regimen in use, dosage and type

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### 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 mismatch 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)
- If feeding is interrupted, for example, due to a blocked feeding tube or if the tube is 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.

### Fluids and dehydration risk

Lack of fluids and possible dehydration is challenging for an individual in the last days of life. The withdrawal of fluids is controversial. Fluids should be withdrawn unless it is the expressed wish of the individual, if they lack the capacity to decide this then family and or carers should be consulted<sup>34,35</sup>. No evidence exists to support whether the withdrawal of fluids will hasten death or that the offering of clinical rehydration prolongs life. If the individual is demonstrating marked signs and symptoms of dehydration such as thirst, delirium or inability to speak because of dry mouth a therapeutic trial of clinically assisted rehydration should be considered, and the individual reviewed over a 12-hour time span. If there are signs of harm including fluid overload or if the person requests that they no longer wish for fluids, they should be discontinued<sup>31</sup>.

# 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)

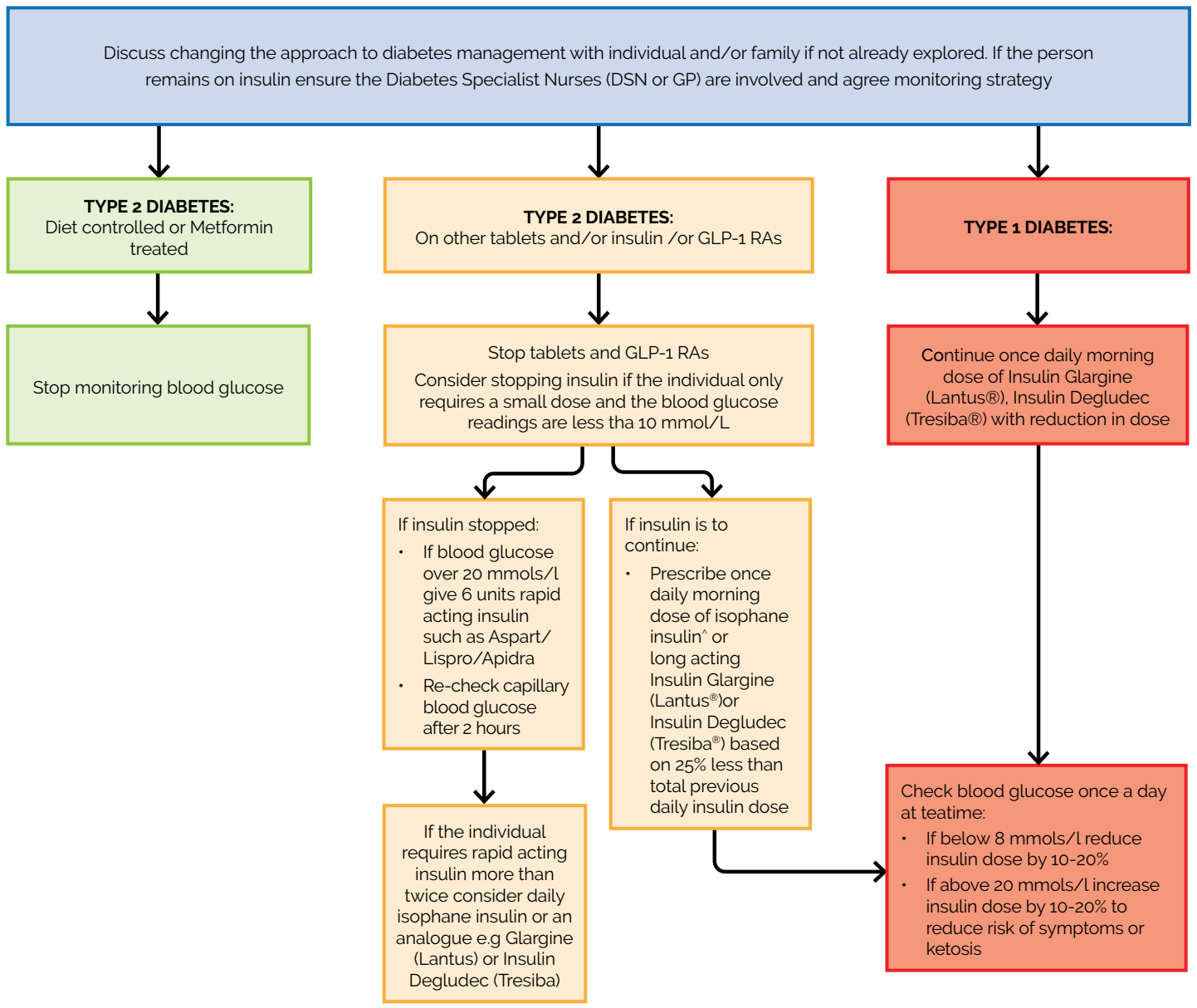
An EHCP makes communication easier in the event of a healthcare emergency. Tackling an EHCP includes shared decision making and recording around expectations and capabilities of the individual and carers in the event of predictable situations or emergencies. The plan should include a list of regular 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>

**ReSPECT** (Recommended Summary Plan for Emergency Care and Treatment) is a process for developing personalised recommendations for a person's clinical care and treatment if they are unable to participate in decision making. <https://www.resus.org.uk/respect>

Figure 1 - Algorithm for the last days of life



**IMPORTANT INFORMATION:**

- ❗ Aim for capillary blood glucose readings of 6-15 mmol/L
- ❗ 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 person
- ❗ If symptoms are observed it could be due to abnormal blood glucose levels
- ❗ Test urine or blood for glucose if the person is symptomatic
- ❗ Observe for symptoms in previously insulin treated individual 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 use of Dexamethasone has become more common place in the treatment of people diagnosed with the COVID 19 virus. 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 (2021) Management of Hyperglycaemia and Steroid (Glucocorticoid) Therapy<sup>36</sup>.

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

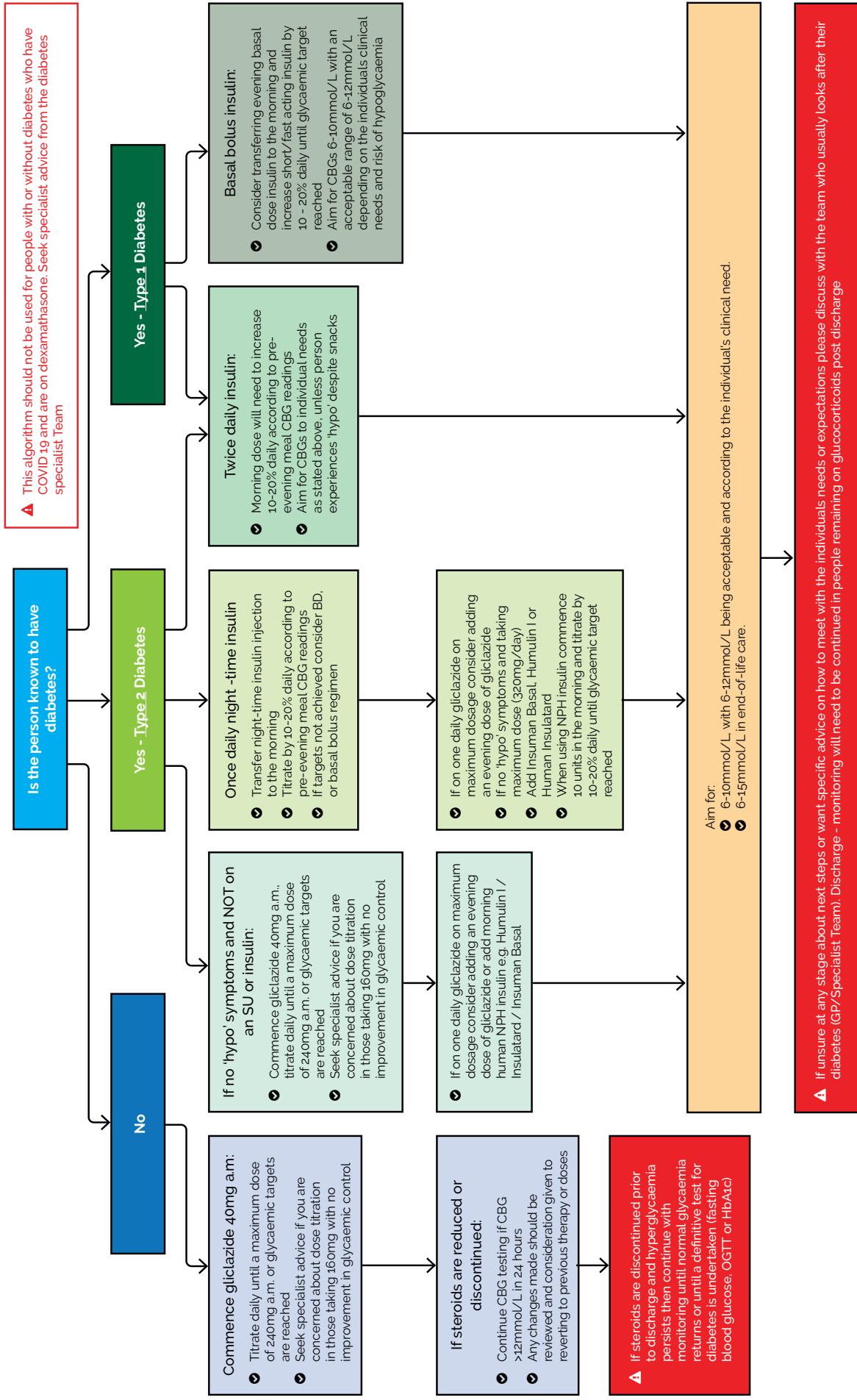
Early discussions with the Diabetes Specialist Team can assist in choosing the more appropriate steroid and blood glucose lowering treatment. Inclusion of therapies for glucose lowering along with steroids in "rescue packs" for COPD can be an effective strategy in self management.

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<sup>®</sup>/Insulatard<sup>®</sup> or Insuman Basal<sup>®</sup>) 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 person it is important to recognise the signs and symptoms of hypoglycaemia and then to:

- Treat appropriately
- Consider reducing insulin and/ or sulphonylureas

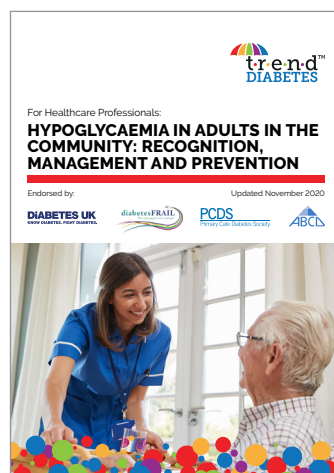
If the person is in their preferred place of death and death is imminent it may be necessary to manage symptoms at home. Likewise if a hospital inpatient is hypoglycaemic despite on-going appropriate iv therapy it may be necessary to stop the active treatment of blood glucose lowering treatment and treat the individual 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 dietitian to assess the impact of nutritional deficits
  - Early identification of risk factors for hypoglycaemia
  - Treat pain effectively
  - Assess impact of weight loss
  - Assess influence of opiates/other pain killers on appetite

**i** For more detailed information on hypoglycaemia management please access [Hypoglycaemia in adults in the community: Recognition, management and prevention at www.trenddiabetes.online](http://www.trenddiabetes.online)



## Identifying those at risk:

These include all insulin preparations, sulphonylurea (e.g. Gliclazide, Glipizide, Glimepiride) 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
- Utonomic neuropathy (gastroparesis)
- Nausea and vomiting
- Previous gastrectomy
- Frailty
- Memory problems
- Oropharyngeal and oesophageal tumours

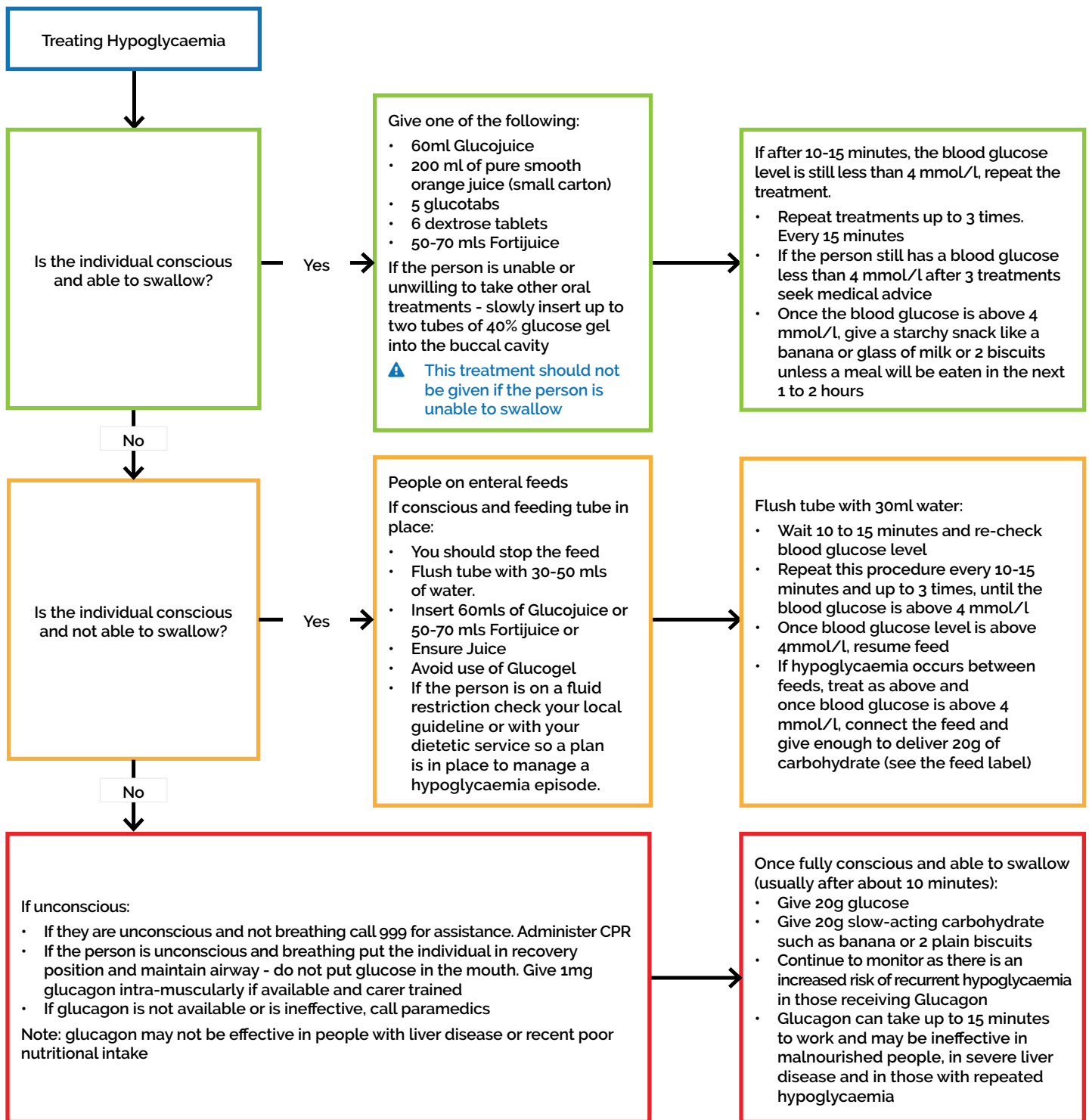


## Identifying hypoglycaemia: signs and symptoms:

- > 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



⚠ Always review medication following an episode of hypoglycaemia : If hypo episode more than once within same time frame with unknown cause consider reducing insulin and/or sulphonylurea doses

# 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	Consider reducing the SU or insulin dose if blood glucose level less than 6mmol/L
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>	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
Stop SGLT2 inhibitor agents and Metformin in acute illness	

Table 4: Type 1 Diabetes: Specific Advice
Test for urine or blood ketones if the individual has symptoms of hyperglycaemia and dehydration.
Type 1 on insulin treatment - continue long acting insulin every day
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 regimen (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 3: Example of Sick-Day Management for End of Life Care Guidance for Healthcare Professionals Information Leaflet

# WITHDRAWAL OF TREATMENT

This section on withdrawal of therapy should be read in conjunction with the section on 'de-intensification of therapy' on page 9. 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 on the evidence available to a clinician
- Where continued use of blood pressure or lipid lowering therapy cannot be justified on cardiovascular or cerebrovascular health benefit considerations
- Where continued food or fluids are causing distress and are not the choice of the individual
- Where continued treatment with insulin in someone with type 2 diabetes poses an unacceptable risk of hypoglycaemia

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 but 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>9,35,36,37</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>38</sup>.

The Neuberger Report<sup>39</sup>, 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>34</sup>. The Nursing and Midwifery Council provided a position statement on the care of the dying in response to endorsement of a collaborative report provided by the Leadership Alliance<sup>40,41</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.

Healthcare professionals should all be encouraged to review deaths to facilitate learning by identifying and sharing good practice while considering opportunities to improve care for the next individual

Nursing competencies for care of people with diabetes in end of life care are already available<sup>42</sup>.

**i See Appendix 4 for Staff Competencies**

## SUMMARY



### Recommendations:

These clinical care recommendations address many aspects of care that are generic and equally applicable to end of life scenarios due to other diseases and conditions as well as diabetes. The current guidance for individuals with diabetes who are at end of life have thus attempted to include these as well as more specific emphasis as summarised below:


- The importance of recognising early the need for an end of life management plan irrespective of the clinical or home-based setting
- That palliative care can be implemented at any appropriate time throughout the person's life journey with diabetes
- That effective end of life care should promote comfort and quality of life and address where possible the spiritual and religious needs of the individual
- Clinicians have a continuous responsibility to balance benefits of diabetes interventions with likely prognosis and estimated time of life left
- As end of life approaches to minimise interventions and monitoring to keep the individual free of unnecessary stress without compromising safety (i.e. avoid DKA, hypoglycaemia or other metabolic complications)
- To involve individuals and family in decisions about diabetes management and all end of life care planning
- Recognise that diabetes management requirements can change quickly with steroid use, weight loss, liver or renal disease
- Active involvement of the diabetes specialist nurse and dietitian is recommended especially if the individual has type 1 diabetes or type 2 treated with insulin

## Appendix 1 - Gold standards Framework



**the 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.

**Three trajectories of illness (Lynn et al)**  
reflecting the three main causes of expected death



#### 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.'

#### 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

**Identify**

patients who may be in their last year of life and identify their needs-based code/stage

**Assess**

current and future, clinical and personal needs

**Plan**

living well and dying well

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.

#### 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.



## Supportive and Palliative Care Indicators Tool (SPICT™)



**The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.**

### Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

### Look for clinical indicators of one or multiple life-limiting conditions.

#### Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

#### Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

#### Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

#### Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

#### Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

#### Other conditions

Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

#### Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

#### Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

### Review current care and care planning.

- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.



Please register on the SPICT website ([www.spict.org.uk](http://www.spict.org.uk)) for information and updates.

SPICT™, April 2019

Appendix 3 - Sick day management

**i** For more detailed information on sick day management please access our information leaflets at [www.trenddiabetes.online](http://www.trenddiabetes.online)

**LIFESTYLE**




## TYPE 1 DIABETES: WHAT TO DO WHEN YOU ARE ILL

**> WHY IS THIS LEAFLET FOR YOU?**

Everyone has days when they are not well. If you have diabetes, being unwell can affect your glucose control so it is important that you know how to manage this. This leaflet will give you essential information on:



- How illness affects your glucose levels
- Looking after yourself
- Managing your insulin
- What to eat and drink
- Being prepared
- When to seek help



The content of this leaflet was generated independently by Trend Diabetes. Printing and distribution was funded by Novo Nordisk

Date of preparation: March 2020

**LIFESTYLE**




## TYPE 2 DIABETES: WHAT TO DO WHEN YOU ARE ILL

**> WHY IS THIS LEAFLET FOR YOU?**

Everyone has days when they are not well. If you have diabetes, being unwell can affect your blood glucose control so it is important that you know how to manage this. This leaflet will give you essential information on:

- How illness affects your blood glucose levels
- Looking after yourself
- What to eat and drink
- Managing your medication
- When to seek help



The content of this leaflet was generated independently by Trend Diabetes. Printing and distribution was funded by Napp. Napp have reviewed the content for factual accuracy only.

UK/DIA - 18080(1)  
March 2020



## 27. END OF LIFE CARE

To care for someone with diabetes at the end of their life, you should be able to:	
<b>1. Unregistered practitioner</b>	<ul style="list-style-type: none"> <li>Undertake blood glucose monitoring as agreed between the individual and diabetes team.</li> <li>Document blood glucose results and report those that are outside the agreed target range to a registered nurse.</li> <li>Be aware of policies relating to end-of-life care and diabetes.</li> <li>List the signs and symptoms that may indicate hypoglycaemia or hyperglycaemia.</li> <li>Be aware of the need to avoid dehydration on people in the last weeks and days of life</li> </ul>
<b>2. Competent nurse</b>	<p>As 1, and:</p> <ul style="list-style-type: none"> <li>Be able to discuss document relating to advance directives, Emergency health care planning and ReSPECT forms</li> <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 daily basis.</li> <li>Demonstrate knowledge of appropriate blood glucose targets (e.g. 6 – 15mmol/L) to avoid hypoglycaemia and symptomatic 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 or hospitalisation from hypoglycaemia, hyperglycaemia, DKA or HHS.</li> <li>Be aware that people with type 1 diabetes must remain on insulin therapy during the last few days of life, but they may need a change in insulin type and regimen depending on their eating pattern.</li> <li>Recognise that people with type 2 diabetes may not need treatment for diabetes in the last few days of life.</li> <li>Be aware that, where possible, diabetes treatment plans and medication changes must be discussed with the individual and significant others.</li> <li>Be aware of the 4 stages (A-D Gold Standard Framework) for considering the use of glucose lowering therapies.</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 significant others, including Advanced Care Planning.</li> <li>Describe indications for the initiation or discontinuation of blood glucose-lowering agents.</li> <li>Advise on the necessity and frequency of blood glucose monitoring, in agreement with the individual and significant others.</li> <li>Recognise when treatment needs to be adjusted.</li> <li>Monitor and support junior staff to ensure they have appropriate competence.</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 about 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 competence and scope of practice.</li> <li>Participate in the development of guidelines and protocols related to diabetes and palliative care.</li> </ul>
<p><b>Suggested examples to assess competence in this area:</b></p> <ul style="list-style-type: none"> <li>✓ Provide examples of anonymous care plans demonstrating appropriate advice and management of diabetes given to people with a few months of life to a few days.</li> </ul>	<p><b>Useful resources:</b></p> <p>End of Life diabetes care: clinical care recommendations. 4rd edition available at <a href="http://www.trenddiabetes.online/resources/">www.trenddiabetes.online/resources/</a></p> <p><a href="https://www.goldstandardsframework.org.uk/advance-care-planning">https://www.goldstandardsframework.org.uk/advance-care-planning</a></p> <p><a href="https://www.rcn.org.uk/clinical-topics/end-of-life-care/advance-care-planning">https://www.rcn.org.uk/clinical-topics/end-of-life-care/advance-care-planning</a></p>

## USEFUL RESOURCES

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- i** Ambitions for Palliative and End of Life Care [www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk)
- i** 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)
- i** Commissioning for Diabetes End of Life Care Services February 2010. NHS Diabetes [www.diabetes.nhs.uk/commissioning\\_resource](http://www.diabetes.nhs.uk/commissioning_resource)
- i** Gold Standards Framework: [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)
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- i** Scotland End of Life Care Strategy 2008: [www.palliativecarescotland.org.uk/publications/Palliative%20and%20End%20of%20Life%20Care%20in%20](http://www.palliativecarescotland.org.uk/publications/Palliative%20and%20End%20of%20Life%20Care%20in%20)
- i** Trend Diabetes - Hypo, Illness, and Steroid Leaflets [www.trenddiabetes.online](http://www.trenddiabetes.online)

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