



For Healthcare Professionals:

END OF LIFE GUIDANCE FOR DIABETES CARE

CONCISE VERSION

Endorsed by:

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WELCOME AND STATEMENT

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 health care professionals who are not specialists in diabetes care, 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.

i This concise document focuses on glycaemic management. A more detailed document including information on specific comorbidities is available at www.trenddiabetes.online

The recommendations are updated regularly and this is the 5th edition. We are delighted to carry on with the excellent work undertaken initially by Diabetes UK in the development of the original document.

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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.

Simon O'Neill

Director of Care and Clinical Intelligence

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 is one of two, a concise version focusing on glycaemic management and a more detailed version which encompasses information a sample selection of key-morbidities related to diabetes management. Both documents provide an update to the excellent resources produced by originally by Diabetes UK in 2013¹. 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 life².

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 diabetes³. 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 and cancers.

These timely revisions 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 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 section on training and education of the healthcare workforce is included⁴.

This updated guidance summarises major glycaemic problems that individuals with diabetes at the end of life experience and how these are best managed.

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 these type of documents 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 these documents as a summaries 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

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This document is available at www.trenddiabetes.online. Access to these resources is free of charge to anyone registering as a member of Trend Diabetes. Any replication of these materials must be referenced to the source document.

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 events⁴**

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 enables 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 Guidance⁴ and the Supportive and Palliative Care Indicators Tool (SPICT)⁵ 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 on page 25 for Proactive Identification Guidance and Appendix 2 on page 27 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 home⁴

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)⁴

i See Appendix 1 on page 25 for Proactive Identification Guidance and Appendix 2 on page 27 for SPICT.

This model has been adapted in Canada⁶, Australia⁷, New Zealand⁸ 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 β -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. This also applies to out-of-hospital hypoglycaemia⁹.

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

These 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 recommendations are 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 planning¹

Principles of High Quality Diabetes Care at the End of Life

These are to:

- Support and maintain the empowerment of the individuals (in their diabetes self-management) and carer for as long as possible¹
- Ensure that effective symptom control is provided during the dying stage
- Tailor glucose-lowering therapy and minimise 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

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, 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 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 and 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 diabetes¹.

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, 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 the 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 decision making. 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 family²⁰. 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)³.

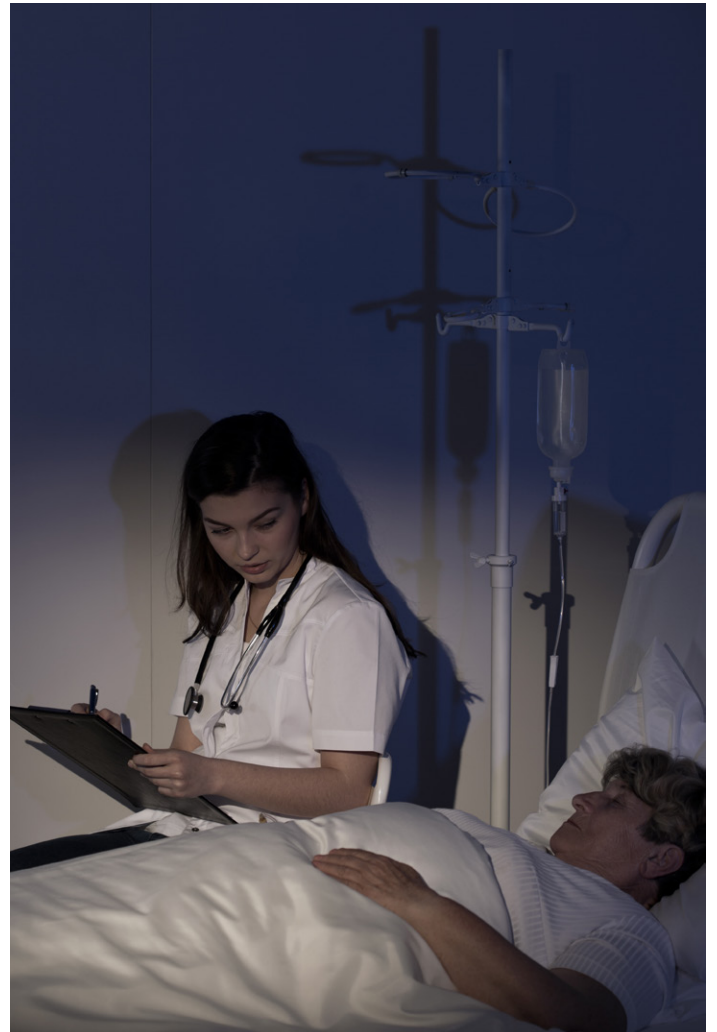
Insulin should be maintained in those with type 1 diabetes as withdrawing insulin treatment before the person has died could lead to diabetic ketoacidosis (DKA). A shift to a simpler regimen, such as once daily basal insulin, may be preferential in someone who is in the last days of their life.

DKA causes severe hyperglycaemia and dehydration so should be avoided. 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 adverse effects on appetite and associated weight loss and/or Sodium-glucose co-transporter-2 (SGLT2) inhibitors because of possible adverse effects on fluid balance and the risk of urogenital infections.

Lipid-lowering agents such as statins can be considered for withdrawal because of unlikely benefits and the reduction of possible 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^{10,11}.

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 adults²² and NG 142²³. 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 Framework⁴)** within the end of life scenario for considering the use of glucose-lowering therapies and other relevant drug therapies: these are colour coded in line with other nationally recognised stages of end of life care:

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

A. Blue: "All" from diagnosis stable with year plus prognosis

The use of cardio-protective therapies (e.g. ACE inhibitors, angiotensin-receptor blockers, aspirin, statins) should be reviewed in the light of the diagnosis and the presence of other medical co-morbidities, and dosage reductions (even withdrawal) of some of the therapies considered.

Individuals may experience more gastrointestinal effects from aspirin with poor dietary intake or concurrent steroid use. These people 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) and then 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 / GLP 1-RA-GIP 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 which treatment regimen to recommend¹.

Table 1: Medicines Management – Non - Insulin therapies

Metformin: <ul style="list-style-type: none"> Standard Metformin Glucophage SR 	Sulfonylurea: <ul style="list-style-type: none"> Gliclazide Glipizide Glimepiride Repaglinide Tolbutamide 	Pioglitazone	Gliptins: <ul style="list-style-type: none"> Alogliptin Linagliptin Saxagliptin Sitagliptin 	Other non insulin therapies: <ul style="list-style-type: none"> Bydureon Dulaglutide Exenatide Liraglutide Lixisenatide Rybelsus Semaglutide Tirzepatide 	SGLT2 inhibitors: <ul style="list-style-type: none"> Canagliflozin Dapagliflozin Empagliflozin Ertugliflozin
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Risk of hypoglycaemia with non insulin therapies when used as mono therapy

✗ No Risk	✓ Moderate Risk	✗ No Risk	✓ Low risk	✗ No risk	✓ Low risk
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General Considerations

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 ²	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 if symptoms persist despite using Metformin MR consider withdrawing this drug		Should not be used in individuals with or at risk of bladder tumour or heart failure	Combination with sulfonylurea 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. Withdraw SGLT2i therapy if the individual has Covid due to the risk of clinical dehydration leading to DKA

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 individuals with type 2 diabetes 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 glucose levels 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, but insulin should always be continued for those with type 1 diabetes.

Some individuals with type 2 diabetes may achieve revised targets without insulin injections. 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. Continuous glucose monitoring (icCGMS) 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 in those undertaking 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 (Humulin I) (cloudy insulin) in combination with daytime oral hypoglycaemic drugs may be a good first line treatment choice in individuals with type 2 diabetes and symptomatic hyperglycaemia
- 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 CGMS and adjusting bolus doses according to the carbohydrate content of their food. This 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.

Glucose sensor technology

Increasingly individuals are using newer methods of glucose testing including real time CGMS (rtCGMS) or Interstitial Flash glucose monitoring (isCGM). These devices enable monitoring without the need to do frequent finger prick tests and so are less invasive. They are recommended for people with type 1 diabetes or type 2 diabetes who are insulin treated. 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 Insulin Glargine, Toujeo 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 may 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 17) , 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^{12,13}. 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.

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 or the person is unable to speak because a dry mouth, and oral hydration is 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 harm including fluid overload or if the person requests that they no longer wish for fluids, they should be discontinued¹⁴.

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 sulfonylurea 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 reduced 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 glucose levels)
- To manage symptoms of high glucose levels

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 glucose levels 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 glucose then insulin therapy is needed. For more information access: <https://trenddiabetes.online/portfolio/diabetes-and-enternal-feeding/>

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 glucose levels may drop too low or rise too high. The table below gives some common feed and insulin regimens¹⁵:

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. JBDS enteral feeding guidance can be accessed at <https://abcd.care/resource/current/jbds-05-glycaemic-management-during-enteral-feeding-people-diabetes-hospital> . Updated 2024

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

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

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

Hypoglycaemia

Specific 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 not given at the correct time

Signs and symptoms of low glucose levels 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 not 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 consulted¹⁶.

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)

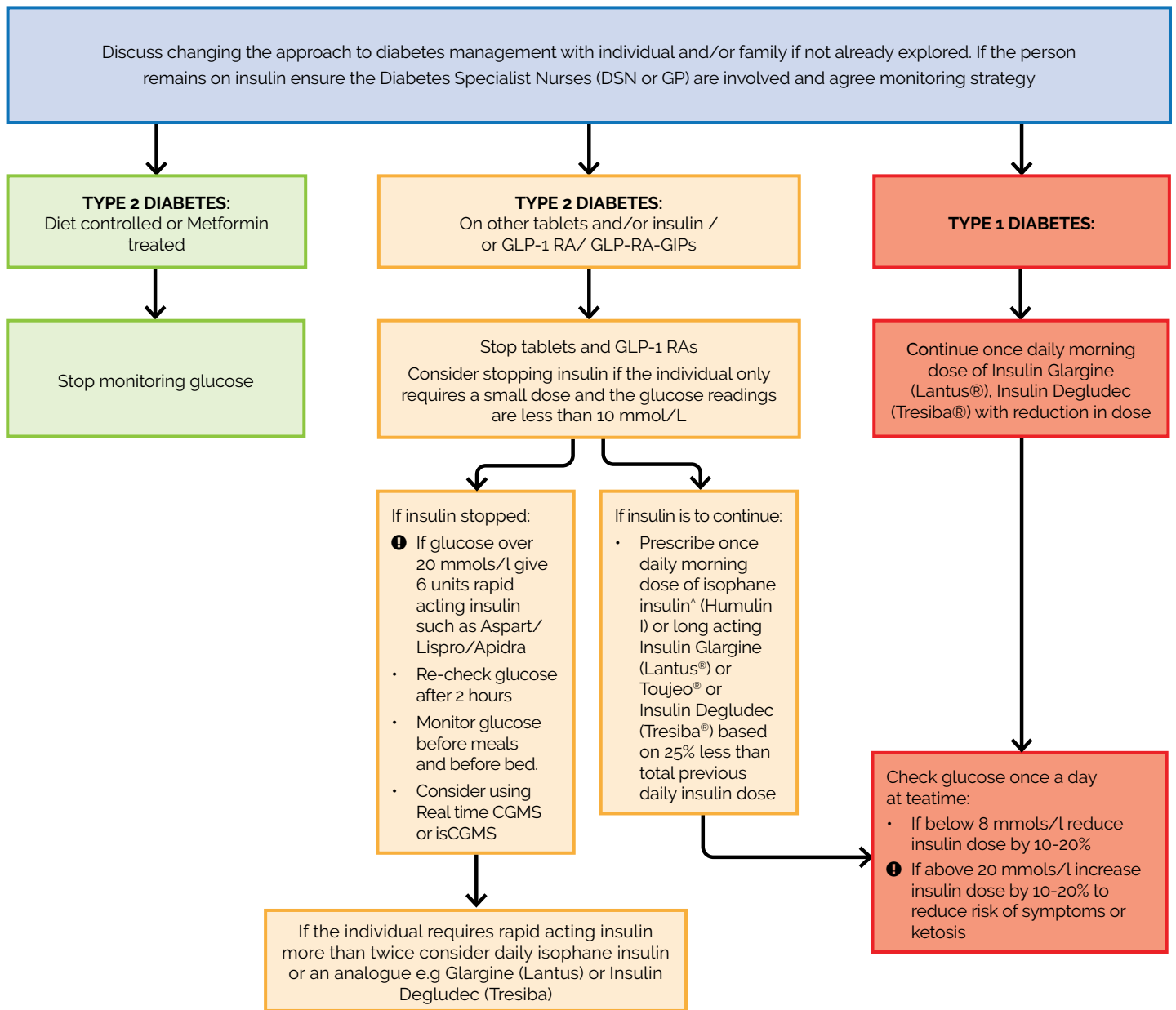
An EHCP makes communication easier in the event of a healthcare emergency. Tackling an EHCP includes shared decision making and recording around expectations and capabilities of the individual and carers in the event of predictable situations or emergencies. The plan should include a list of regular 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 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 glucose levels
- ❗ 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 glucose levels
- ❗ Test blood for glucose if the person is symptomatic
- ❗ Observe for symptoms in previously insulin treated individual where insulin has been discontinued
- ❗ rtCGMS or isCGM glucose monitoring may be useful in these individuals to avoid finger prick testing
- ❗ **Be aware when adjusting insulin doses to address hyperglycaemia in individuals at risk of insulin sensitivity such as those with CKD, cancer or frailty that dose adjustment will need to be in line with their specific clinical needs**

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 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 sulfonylurea (e.g. Gliclazide) or morning isophane insulin (e.g. Humulin I). See Figure 2 for managing individuals on once daily steroid on page 19¹⁷.

JBDS (2023) Management of Hyperglycaemia and Steroid (Glucocorticoid) Therapy¹⁶.

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

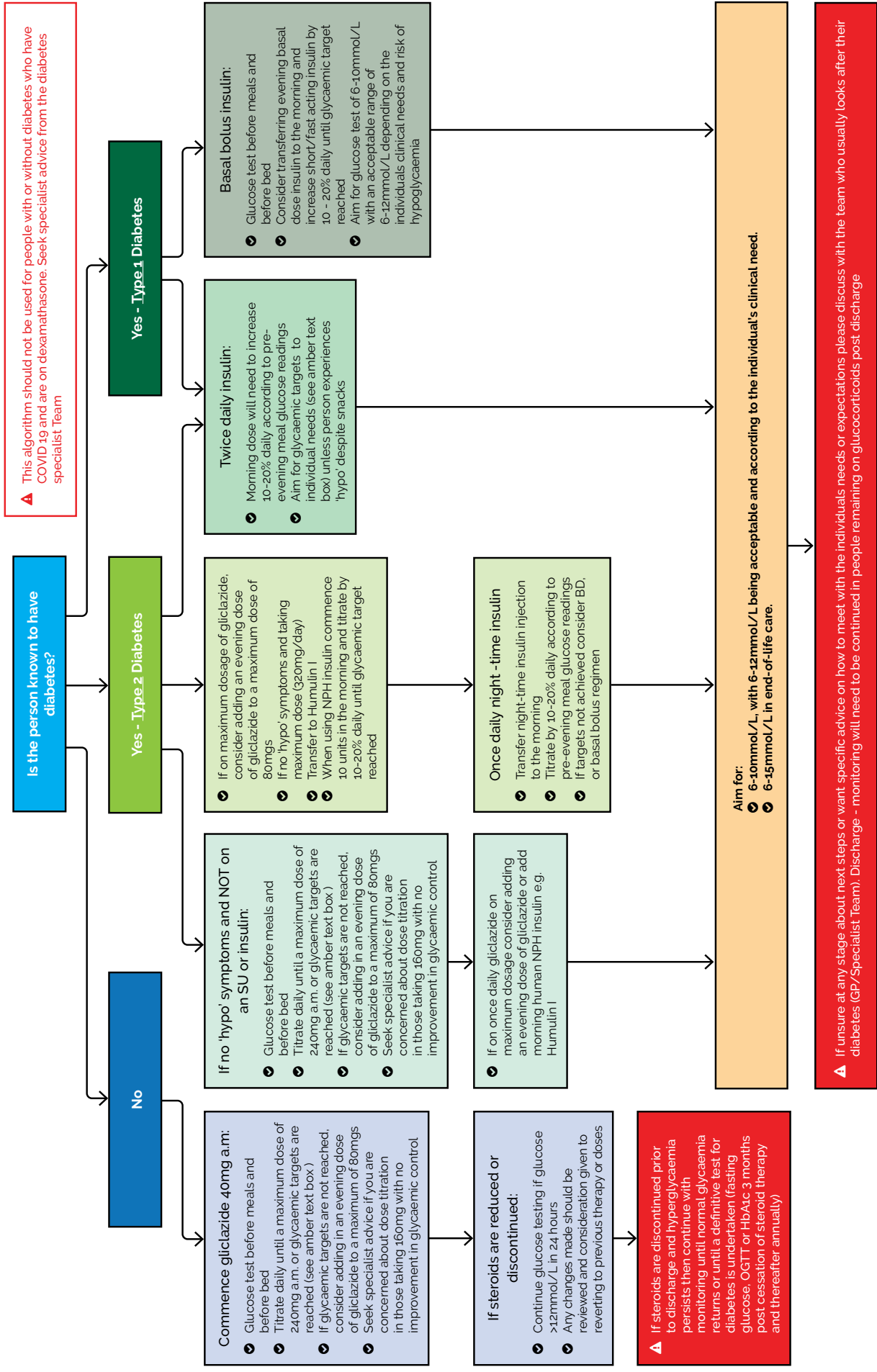
Early discussions with the Diabetes Specialist Team can assist in choosing the more appropriate steroid and glucose lowering treatment. Inclusion of therapies for glucose lowering along with steroids in "rescue packs" for COPD can be an effective strategy in self management.

Short-term courses (less than 3 days) of steroids for example in those undertaking chemotherapy 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[®]) given once daily should be considered.

Individual on high dose corticosteroid treatment as part of cancer treatment regular screening for glucose for the duration of the treatment cycle.



Figure 2 - Algorithm for Managing Glucose with Once Daily Steroid Therapy¹⁷



HYPOGLYCAEMIA

In a dying person it is important to recognise the signs and symptoms of hypoglycaemia and then to:

- a. Treat appropriately
- b. Consider reducing insulin and/ or sulfonylurea

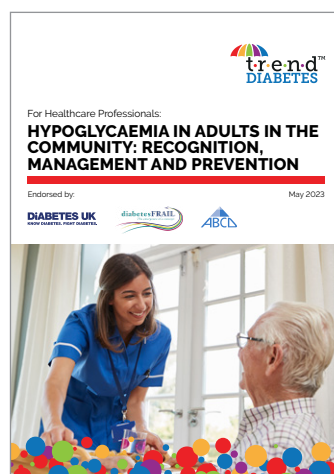
If death is imminent it may be necessary to manage symptoms at home. Likewise if a hospital inpatient is hypoglycaemic despite on-going appropriate iv glucose therapy it may be necessary to stop the active treatment of glucose lowering treatment and treat the individual symptomatically.

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. 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, sulfonylurea (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:

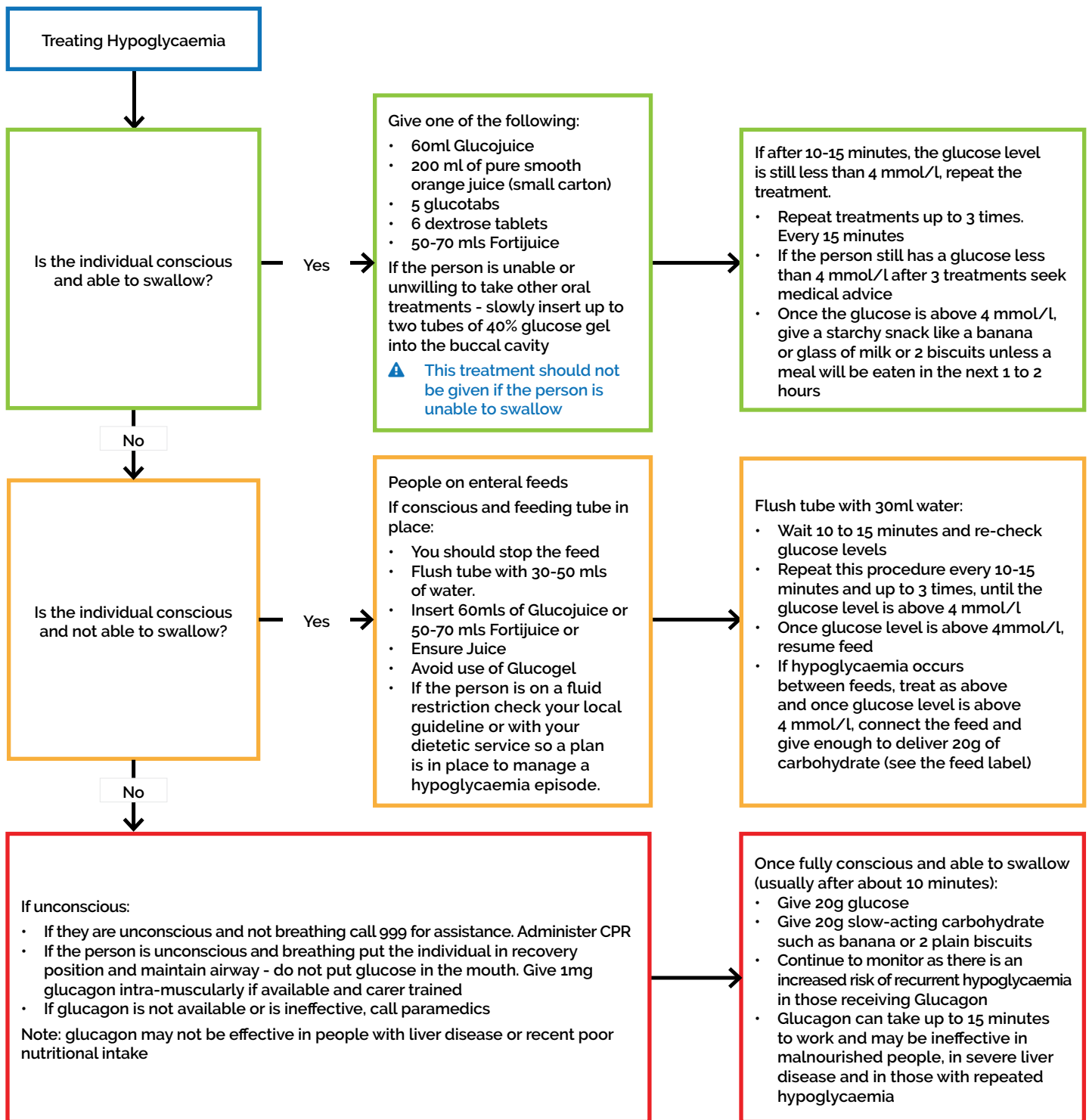
- Poor appetite/erratic eating pattern
- Weight loss
- Renal deterioration
- Liver impairment/carcinoma
- Utonomic neuropathy (gastroparesis)
- Nausea and vomiting
- Previous gastrectomy
- Frailty
- Memory problems
- Oropharyngeal and oesophageal tumours



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, 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 sulfonylurea 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 sulfonylurea or prandial regulators	Type 2 diabetes on a sulfonylurea, prandial regulator and/or insulin or GLP1 Agonist
Keep on usual diabetes medication	Check glucose levels 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 glucose levels are above 15 mmol/L)
Observe for signs and symptoms of hyperglycaemia and dehydration	Consider reducing the SU or insulin dose if glucose levels are less than 6mmol/L
Only check the glucose to confirm hyperglycaemia: <ul style="list-style-type: none"> • Aim to maintain glucose levels between 6-15 mmol/L or less • If glucose levels > 15 mmol/L consider giving insulin 	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 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 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 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)

i Appendix 3: Example of Sick-Day Management for End of Life Care Guidance for Healthcare Professionals Information Leaflet on page 28

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



⚠ Care after death: From September 2024 every death in England and Wales will be scrutinised by a Medical Examiner and/ or Coroner. Under the new legislation, an attending doctor who has seen the person alive during their lifetime may be asked to complete the medical certificate of cause of death. That will include those who have seen patients seen in hospital or in outpatient settings²³: www.legislation.gov.uk/ukxi/2024/492/made

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 skills for care^{12,13,18,19,20}.

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 area²¹.

The Neuberger Report¹⁶, 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 revalidation²¹. 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 Alliance²¹. 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 available²².

i See Appendix 4 for Staff Competencies on page 29.

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)



RCGP Royal College of
General Practitioners

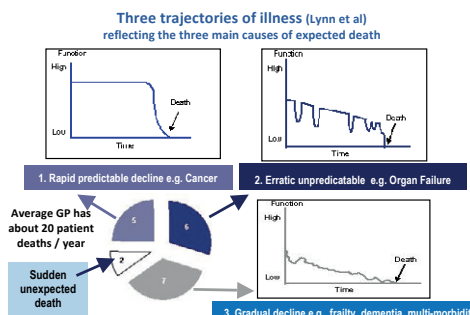
The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life leading to improved proactive person-centred care

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.

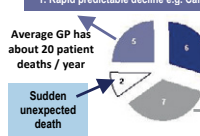
Three trajectories of illness (Lynn et al)
reflecting the three main causes of expected death



1. Rapid predictable decline e.g. Cancer 2. Erratic unpredictable e.g. Organ Failure

3. Gradual decline e.g. frailty, dementia, multi-morbidity

Average GP has about 20 patient deaths / year



Sudden unexpected death

National Policy support for earlier identification.

General Medical Council – 2010

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

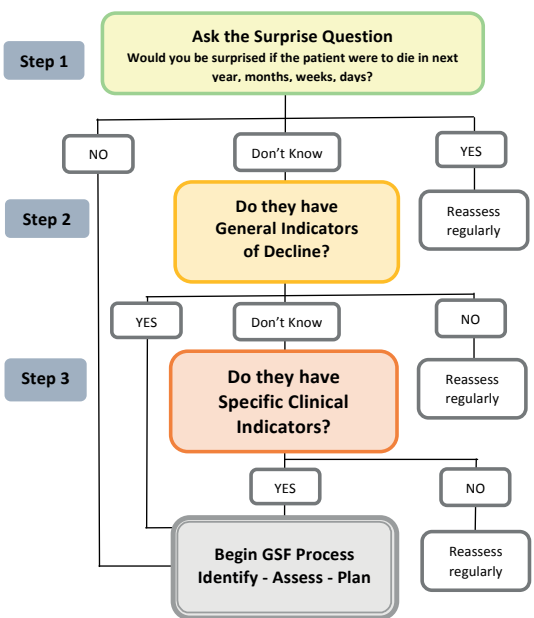
Identify
patients who may be in their last year of life and identify their needs-based code/stage

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 For more details contact 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.

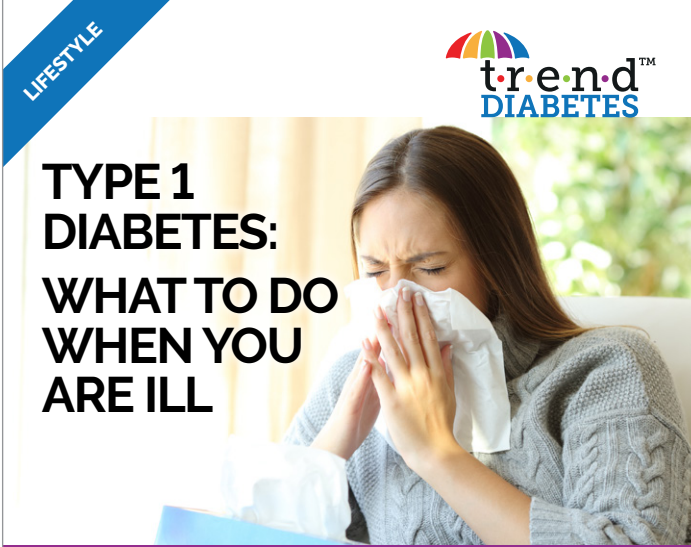
- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family 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) 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



LIFESTYLE


**trend™
DIABETES**

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



LIFESTYLE

**trend™
DIABETES**

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 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
- What to eat and drink
- Managing your medication
- When to seek help

27. END OF LIFE CARE²¹

To care for someone with diabetes at the end of their life, you should be able to:	
1. Unregistered practitioner	<ul style="list-style-type: none"> Undertake glucose monitoring as agreed between the individual and diabetes team. Document glucose results and report those that are outside the agreed target range to a registered nurse. Be aware of policies relating to end-of-life care and diabetes. List the signs and symptoms that may indicate hypoglycaemia or hyperglycaemia. Be aware of the need to avoid dehydration on people in the last weeks and days of life
2. Competent nurse	<p>As 1, and:</p> <ul style="list-style-type: none"> Be able to discuss document relating to advance directives, Emergency health care planning and ReSPECT forms Assess the person's needs and ensure they are pain-free, adequately hydrated and symptom-free from their diabetes. Be aware that palliative care may vary in time, and diabetes control needs to be assessed on an individual and daily basis. Demonstrate knowledge of appropriate glucose targets (e.g. 6 – 15mmol/L) to avoid hypoglycaemia and symptomatic hyperglycaemia. Be aware that glucocorticoid steroids may cause diabetes, which may require insulin treatment. Steroids can also worsen glycaemic control with pre-existing diabetes. Be aware that the aim of diabetes treatment in the last few days of life is to prevent discomfort or hospitalisation from hypoglycaemia, hyperglycaemia, DKA or HHS. 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. Recognise that people with type 2 diabetes may not need treatment for diabetes in the last few days of life. Be aware that, where possible, diabetes treatment plans and medication changes must be discussed with the individual and significant others. Be aware of the 4 stages (A-D Gold Standard Framework) for considering the use of glucose lowering therapies.
3. Experienced or proficient nurse	<p>As 2, and:</p> <ul style="list-style-type: none"> Initiate and develop personalised care plans in collaboration with the person with diabetes and significant others, including Advanced Care Planning. Describe indications for the initiation or discontinuation of glucose-lowering agents. Advise on the necessity and frequency of blood glucose monitoring, in agreement with the individual and significant others. Recognise when treatment needs to be adjusted. Monitor and support junior staff to ensure they have appropriate competence.
4. Senior practitioner or expert nurse	<p>As 3, and:</p> <ul style="list-style-type: none"> Plan, implement and deliver education programmes about diabetes and palliative care for other HCPs. If a registered non-medical prescriber, adjust and prescribe medication related to diabetes, as required, within own competence and scope of practice. Participate in the development of guidelines and protocols related to diabetes and palliative care.
Suggested examples to assess competence in this area:	Useful resources:
<ul style="list-style-type: none"> ✓ 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. 	<p>End of Life diabetes care: clinical care recommendations. 4rd edition available at www.trenddiabetes.online/resources/</p> <p>https://www.goldstandardsframework.org.uk/advance-care-planning</p> <p>https://www.rcn.org.uk/clinical-topics/end-of-life-care/advance-care-planning</p>

USEFUL RESOURCES

- i** Ambitions for Palliative and End of Life Care www.endoflifecareambitions.org.uk
- i** End of Life Care Strategy www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277
- i** Commissioning for Diabetes End of Life Care Services February 2010. NHS Diabetes: diabetes.nhs.uk/commissioning_resource
- i** Gold Standards Framework: www.goldstandardsframework.org.uk
- i** National Audit Office: End of Life Care publication 26 November 2008: www.nao.org.uk/publications/0708/end_of_life_care.aspx
- i** Royal College of General Practitioners. November 2009: www.rcgp.org.uk/college_locations/rcgp_scotland/initiatives/end_of_life_care.aspx
- i** Scotland End of Life Care Strategy 2008: www.palliativecarescotland.org.uk/publications/Palliative%20and%20End%20of%20Life%20Care%20in%20
- i** Trend Diabetes - Hypo, Illness, and Steroid Leaflets www.trenddiabetes.online

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