

# **Diabetes Care Towards End of Life** Clinical care recommendations

Developed by the Midlands Diabetes Nurse Specialist Group and HSE Midlands Specialist Palliative Care Service

1st Edition 2022

# **CONTENTS**

Preface	2
Major Contributors & Acknowledgements	3
Introduction	4
Principles of High Quality Diabetes Care Towards the End of Life	6
Stages Towards the End of Life	7
Medicines Management – Non Insulin Therapies	9
Medicines Management – Insulin Therapy	13
Final Days/Terminal Care	15
Flow Chart for Diabetes at End of Life	16
Steroid Therapy	17
Hypoglycaemia	19
Sick Day Management	21
Nutrition	
Advance Healthcare Planning	25
Summary of Clinical Care Recommendations for End of Life Care	26
References and Resources	27
Appendix 1 – Gold Standards Framework	29
Appendix 2 – Insulin	31

# ABBREVIATIONS

BD:	Twice daily
BG:	Blood glucose
CGM:	Continuous glucose monitoring
DKA:	Diabetic ketoacidosis
DPP4 inhibitor:	Dipeptidyl peptidase 4 inhibitor
eGFR:	Estimated glomerular filtration rate
euDKA:	Euglycaemic diabetic ketoacidosis
FPG:	Fasting plasma glucose
GFR:	Glomerular filtration rate
GLP-1RA:	Glucagon-like peptide-1 receptor agonist
HbA1c:	Glycosylated haemoglobin
HHS:	Hyperglycaemic hyperosmolar state
IFG:	Impaired fasting glycaemia
IGT:	Impaired glucose tolerance
IM:	Intramuscular injection
MDI:	Multi daily insulin regimen
MDRD:	Modification of Diet in Renal Disease (MDRD) method of calculating eGFR
OGTT:	Oral glucose tolerance test
OHA:	Oral hypoglycaemic agent
SGLT2i:	Sodium-glucose co-transporter-2 inhibitor
SPC:	Summary of Product Characteristics
TZD:	Thiazolidinedione

# PRFFACE

End of life care involves providing support to allow people to continue to live with dignity, keeping them as comfortable as possible until the end and helping families to deal with this often distressing time. In Ireland, diabetes care towards the end of life is an area lacking in guality standards and guidance on best clinical practice. In the past we have used UK guidelines to direct care.

The Irish Midland Diabetes Nurse Specialist Group and the Midlands Specialist Palliative Care Services have come together to help provide better quality standardised care for Irish people with diabetes as they approach end of life. With permission from the UK steering committee we have adapted their End of Life Diabetes Care, Clinical Care Recommendations<sup>1</sup> to produce this document.

Towards the end of life the focus shifts from prevention of long-term complications associated with diabetes to ensuring that the symptoms of high and low blood glucose levels are controlled and minimised. The priorities become avoiding metabolic decompensation and diabetes - related emergencies. All of this should be achieved with the least invasive testing and minimum effective amount of medication.

We are proud to present these recommendations which we feel will greatly enhance the quality of life of patients with diabetes and a terminal illness, and will also give healthcare professionals greater confidence in dealing with such patients. Being given a terminal diagnosis is usually a seismic shock to patients and their families, and they will need a huge amount of support. We hope these guidelines will help to make their guality of life a top priority, and that they will be able to accept less strict control of their diabetes where appropriate.

In the words of Dame Cicely Saunders, the founder of the modern hospice movement: You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.

# One in fifteen people in Ireland are living with diabetes<sup>2</sup>. In the UK, it is estimated that almost one in seven people who die will have diabetes<sup>1</sup>.

This document aims to provide practical guidance for healthcare professionals caring for individuals living with diabetes towards the end of life, and their families.

# Our aim is to:

- Promote a consistent high quality approach to diabetes care towards the end of life
- Inform the wider healthcare workforce about the key issues of diabetes care towards the end of life that will provide a platform for sensitive, appropriate and supportive care
- Provide guidance for glycaemic targets which aim to avoid symptomatic hyperglycaemia and hypoglycaemia with emphasis on less stringent blood glucose and HbA1c values for those approaching end of life
- Create awareness for the need to provide training and education in end of life diabetes care

## STEERING GROUP

Siobhan Meehan (Chair)	Clinical Nurse Specialist Diabetes, Midlands Diabetes Structured Care Programme (MDSCP)
Dr Michael Cushen	Consultant in Palliative Medicine, Midland Regional Hospitals at Portlaoise and Tullamore (MRHP and MRHT)
Demelza Dooner	Advanced Nurse Practitioner Diabetes, MRHT
Georgina Doyle	Advanced Nurse Practitioner Diabetes, MRHP
Mairead Walsh	Clinical Nurse Specialist Diabetes, MDSCP

# MIDLANDS DIABETES NURSE SPECIALIST GROUP MEMBERS

Elaine Bannon	Clinical Nurse Specialist Diabetes, MDSCP
Cassandra Campion	Diabetes Nurse Specialist, MRHT
Maeve Dempsey	Clinical Nurse Specialist Diabetes, Regional Hospital Mullingar (RHM)
Susan Haverty	Clinical Midwife Specialist Diabetes, MRHP
Regina Healion	Clinical Nurse Specialist Diabetes, MRHP
Catherine Hennessy	Diabetes Nurse Specialist, RHM
Siobhan McCann	Clinical Nurse Specialist Diabetes, MRHP
Margaret McEvoy	Clinical Nurse Specialist Diabetes, MRHP
Mairead Mannion	Clinical Nurse Specialist Diabetes, MDSCP
Yvonne Reidy	Clinical Nurse Specialist Diabetes, RHM

# MAJOR CONTRIBUTORS

Amie Giles	Senior Pharmacist, MRHT
Dr Ultan Healy	Consultant Endocrinologist, RHM
Dr Shu Hoashi	Consultant Endocrinologist, RHM
Dr Pauline Kane	Consultant in Palliative Medicine, RHM
Caoimhe Kenny	Senior Dietitian, MRHP
Dr Ma Pyeh Kyithar	Consultant Endocrinologist, MRHP
Dr Joanna McGlynn	Consultant Geriatrician, MRHT
Dr Patrick Murphy	Consultant Physician, MRHT
Dr Jayant Sharma	Consultant Endocrinologist, MRHP
Susan Spollen	Chief 1 Pharmacist, MRHT

# ACKNOWLEDGEMENTS

June James, Nurse Consultant in Diabetes, University Hospitals of Leicester NHS Trust Diabetes Nurse Specialist Team, Sligo University Hospital Caroline Gettings, Clinical Nurse Specialist Palliative Care, RHM Anne Tan, CNM III, Laois Offaly Specialist Palliative Care Team Carol Lynam, CNM III, Longford Westmeath Specialist Palliative Care Team Drug and Therapeutics Committees MRHP, MRHT, RHM

Thanks to Shay Kennedy, MacArt, Dublin for his creativity and design

# **INTRODUCTION**



# **DEFINITION:**

Individuals are 'approaching the end of life' when they are likely to die within the next 12 - 24 months<sup>3,4</sup>. 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 - 24 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

# **Early Identification**

The Gold Standards Framework for end of life care in the UK (see appendix 1)<sup>5</sup> proposes three triggers that may help the health care professional to determine if the individual is nearing the end of life:

## 1. The "Surprise Question": 'Would you be surprised if this individual were to die in the next year, months, weeks, days'?

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

## 2. General indicators of decline are observed such as deterioration / increasing need / choice for no further active care.

These include:

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

The development of hypoglycaemia in people who have not previously been prone to this is also a poor prognostic sign

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

These relate to specific conditions. Although diabetes is not mentioned, it frequently occurs in association with those conditions specifically mentioned:

- Cancer
- Organ failure (including heart, liver, kidney failure, neurological diseases and COPD)
- Frailty, dementia and multiple morbidity

# PRINCIPLES OF HIGH QUALITY DIABETES CARE TOWARDS THE END OF LIFE

- Focusing on quality of life Liberalising the goals of care
- Simplification of treatment and reduction of medication burden
- De-escalation of treatment towards the end of life

## These principles can be achieved by:

- Ensuring that effective symptom control is provided during the dying stage
- Providing an appropriate level of intervention according to stage of illness, symptom profile and respect for dignity
- Supporting and maintaining the empowerment of the individual (in their diabetes self-management) and carer for as long as is safe
- Tailoring glucose-lowering therapy, adjusting glycaemic targets and minimising diabetes-related adverse treatment effects
- Avoiding metabolic decompensation and diabetes-related emergencies:
  - Frequent and unnecessary hypoglycaemia
  - Diabetic ketoacidosis (DKA)
  - □ Hyperosmolar hyperglycaemic state (HHS)
  - Persistent symptomatic hyperglycaemia
- Managing the effects of other medications such as glucocorticoids
- Avoiding foot complications and pressure sores in frail, bed-bound individuals with diabetes
- Avoiding symptomatic clinical dehydration

# Management Goals in Key Clinical Areas

### **Blood glucose control targets**

The following are the glucose control target ranges, as recommended in the UK guidelines on End of Life Diabetes Care<sup>1</sup>, for those approaching the end of life and taking glucose lowering therapies (including insulin) where there may be a risk of hypoglycaemia. 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.

- Aim 1 no blood glucose level less than 6 mmol/l
- Aim 2 no blood glucose level higher than 15 mmol/l

It should be remembered that many individuals with existing diabetes will be aware of blood glucose targets previously set and will need explanation and reassurance to agree a new set of targets.

Non-insulin glucose lowering therapies can be reduced and eventually stopped depending on factors such as poor appetite and weight loss. It may be necessary to discontinue insulin treatment in people with Type 2 diabetes, but insulin should never be stopped in those known to have Type 1 diabetes.

## **Other Medication**

Once it has been recognised that a person is approaching end of life, a review of all prescribed medication is indicated. This decision should be taken in conjunction with the individual and their family to avoid giving the impression that their healthcare professionals are "giving up" on them.

Diabetes Care Towards End of Life Clinical Care Recommendations 2021

# A - Less than 2 years to end of life

Oral hypoglycaemic agents (OHAs)/insulin should be reviewed and targets for blood glucose control reassessed. Anorexia or weight loss may require lower doses of OHAs/insulin.

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.

# **B** - Months to end of life - unstable / advanced disease

# **Type 1 diabetes**

At this stage the aim is to keep drug interventions to a minimum that will control symptoms.

It is generally simpler for individuals to switch from a multi daily insulin regimen (MDI) to a once or twice daily insulin regimen

When switching from a multi daily insulin regimen it is recommended that the total daily insulin dose be reduced by 20-30%

When switching from a twice daily insulin regimen to a basal insulin it is recommended that total insulin daily dose be reduced by 20-30%<sup>1</sup>

The likelihood of carers being involved in insulin therapy administration increases at this stage and may inform the choice of insulin regimen.

Consultation with the diabetes team is recommended

# **Type 2 diabetes**

At this stage the aim is to keep drug interventions to a minimum that will control symptoms.

Complex treatment regimens should be reviewed especially where individuals are on multiple oral hypoglycaemic agents with or without insulin.

For some individuals a once daily insulin regimen may be preferable to multiple oral hypoglycaemic agents

Some Individuals with Type 2 diabetes may choose to take oral agents only.

The likelihood of carers being involved in medication administration increases at this stage and may inform the choice of medication regimen.

Consultation with the diabetes team is recommended

# **C** - Weeks to end of life - deteriorating condition

Individuals may present or be referred to the diabetes team at this time, in which case all of the changes suggested in **A** (Blue box) and **B** (green box) should be considered but keeping in mind that there may be little time to get used to a new insulin regimen.

Managing diabetes can be an added stress at an emotional time for individuals and carers.

Relaxing blood glucose 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 - Final days / terminal care - days prognosis

Ideally by this stage diabetes treatment has been minimised so that few changes are needed in the last days of life.

The Flowchart for Diabetes at End of Life (page 16), 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 aim of the flowchart is to minimise symptoms of diabetes and keep invasive testing to a minimum.

# **MEDICINES MANAGEMENT -**NON INSULIN THERAPIES<sup>6,7</sup>

Individuals with Type 2 diabetes can progress from being diet controlled to commencing on oral agents, usually starting with metformin, with the addition of other agents to achieve the desired individualised HbA1c target.

Towards the end of life, glycaemic targets and diabetes medications need to be discussed and reviewed. The aim is to reduce symptoms of hyperglycaemia, avoid hypoglycaemia and minimise side effects.

As appetite reduces and weight drops, agents such as GLP-1 receptor agonists or SGLT2 inhibitors that promote satiety and weight reduction may no longer be required and may even be contraindicated.

If maintaining hydration is a problem, SGLT2 inhibitors, which have a diuretic effect, are contraindicated.

Not all agents when used alone cause hypoglycaemia, and this may be an important factor in deciding what to use.

## Non - Insulin therapies

Please note that eGFR may not give an accurate measurement of renal function, especially in patients with weight loss. Go to the end of this section (bottom of page 12) for further information.

Drug class	Risk of hypoglycaemia	Renal considerations	Hepatic and other considerations
<b>Biguanides</b> • Metformin	No	eGFR 45-60 : up to 1g bd eGFR 30-45 : 500mg bd eGFR<30 : stop due to risk of lactic acidosis	Review if gastrointestinal symptoms present (nausea, vomiting, loss of appetite, heartburn or diarrhoea). Review in frail individuals.
			Contraindicated in: • Hepatic impairment • Liver metastases • Acute alcohol intoxication • Alcoholism
Sulphonylureas <ul> <li>Gliclazide</li> <li>Glimepiride</li> </ul>	Yes		Review if dietary intake is reduced and/or there is significant weight loss due to increased risk of hypoglycaemia
		<ul> <li>Use with caution in renal failure</li> <li>Consider avoiding use of Gliclazide MR in renal failure</li> </ul>	Contraindicated in severe hepatic impairment
<b>Glinides</b> • Repaglinide	Yes		Review if dietary intake is reduced and/ or there is significant weight loss due to increased risk of hypoglycaemia
		Use with caution in renal failure	Caution in moderate hepatic failure, contraindicated in severe hepatic failure

Risk of Drug class hypoglycaemia con **DPP4** Inhibitors Low • Linagliptin • Saxagliptin • Sitagliptin Linagliptin • Vildagliptin Can be used renal diseas Saxagliptir  $eGFR \ge 45$  : eGFR < 45 : Avoid use ir Sitagliptin eGFR≥45: eGFR 30-45 eGFR < 30 Vildaglipti eGFR ≥50 : eGFR<50:5 Thiazolidinediones No dose adi (TZD's) No necessary. • Pioglitazone

9

Diabetes Care Towards End of Life Clinical Care Recommendations 2021

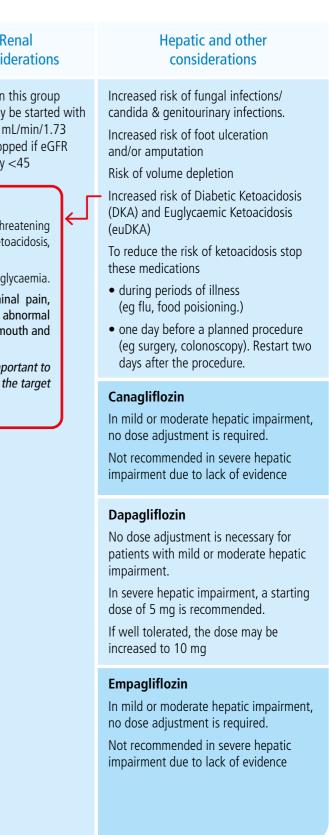
Renal nsiderations	Hepatic and other considerations
	Should not be used in combination with GLP-1 agonists. Discontinue in acute pancreatitis
<b>1</b> d for all stages of e	<b>Linagliptin</b> Pharmacokinetic studies suggest that no dose adjustment is required for patients with hepatic impairment but clinical experience in such patients is lacking.
<b>n</b> : 5mg daily : 2.5 mg daily n haemodialysis	Saxagliptin No dose adjustment is necessary for patients with mild hepatic impairment Use with caution in moderate hepatic impairment Not recommended in severe hepatic impairment.
100mg 5 : 50mg 25mg	Sitagliptin No dose adjustment is necessary for patients with mild to moderate hepatic impairment. It has not been studied in patients with severe hepatic impairment and care should be exercised However, because Sitagliptin is primarily eliminated renally, severe hepatic impairment is not expected to affect its pharmacokinetics
<b>n</b> 50mg twice daily 50mg daily	<b>Vildagliptin</b> Should not be used in patients with hepatic impairment.
justment is usually	May cause fluid retention. Use with caution in individuals with or at risk of heart failure. Contraindicated in established heart failure May cause fractures of small bones, therefore avoid in those at risk of falls or fractures Contraindicated in those with a history of bladder tumour. Pioglitazone should not be used in patients with hepatic impairment

D	ia	b	et
-	10	~	~ ~

Risk of hypoglycaemia	Renal considerations	Hepatic and other considerations		Drug class	Risk of hypoglycaemia	cons
GLP-1 analogues• Dulaglutide• Exenatide• Liraglutide• Semaglutide		Should not be used in combination with DPP4 inhibitors Review in frail individuals Withdraw if abdominal pain or pancreatitis develops	• Car • Dap	Canagliflozin	Low	All drugs in should onl eGFR $\geq$ 60 m <sup>2</sup> and sto persistent
		Review if eating patterns change or significant weight loss occurs.		Diabetic ketoacid	osis (DKA) is an acute	
	<b>Dulaglutide</b> eGFR <15 : avoid use	<b>Dulaglutide</b> - No dose adjustment is required in patients with hepatic impairment		complication of diabetes characterised by hypergl and ketonuria. Euglycaemic DKA (euDKA), is DKA without ma	complication of diabetes characterised and ketonuria. <b>Euglycaemic DKA (euDKA),</b> is DKA	t marked hyper
	<b>Exenatide</b> eGFR <30 : avoid use	<b>Exenatide</b> - No dose adjustment is necessary for patients with hepatic impairment		excessive thirst, rapid laboured breathing, com fatigue, fruity breath odour, sweet or metallic taste change in the odour of urine or sweat If a patient on SGLT2 inhibitors has such symptoms.		
	<b>Liraglutide</b> eGFR <15 : avoid use	Liraglutide - No dose adjustment is recommended for patients with mild or moderate hepatic impairment. Not recommended for use in patients with severe hepatic impairment				level is within
	<b>Semaglutide</b> eGFR <15 : avoid use	Semaglutide - No dose adjustment is required for patients with hepatic impairment. Experience with the use of Semaglutide in patients with severe hepatic impairment is limited.				
	hypoglycaemia	hypoglycaemiaconsiderationsNo	hypoglycaemiaconsiderationsother considerationsNoShould not be used in combination with DPP4 inhibitors Review in frail individuals Withdraw if abdominal pain or pancreatitis develops Review if eating patterns change or significant weight loss occurs.Dulaglutide eGFR <15 : avoid use	hypoglycaemiaconsiderationsother considerationsNoShould not be used in combination with DPP4 inhibitors Review in fail individuals Withdraw if abdominal pain or pancreatitis develops Review if eating patterns change or significant weight loss occurs.Dulaglutide eGFR <15 : avoid use	hypoglycaemia       considerations       other considerations         No       Should not be used in combination with DPP4 inhibitors Review in fail individuals Withdraw if abdominal pain or pancreatitis develops Review if acting patterns change or significant weight loss occurs.       SGL12 inhibitors       Canaglificain         Dulaglutide eGFR <15 : avoid use	hypoglycaemia         Considerations         Other considerations         Drug class         hypoglycaemia           No         Should not be used in combination 

### eGFR = estimated glomerular filtration rate in ml/min/m<sup>2</sup> (using MDRD equation).

If the patient's weight is significantly reduced, this will result in over-estimation of the creatinine clearance, which can be calculated more accurately using formulae such as the Cockcroft-Gault equation. For example, an 85 year old lady with a body weight of 45Kg, and a Creatinine of 130, will have an eGFR of 54.6ml/min/m<sup>2</sup> but a calculated GFR of only 20ml/minute.



Individuals with type 1 diabetes have an absolute requirement for insulin treatment, without which they will rapidly become hyperglycaemic and develop diabetic ketoacidosis (DKA). 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 (HHS), particularly if given corticosteroids. Insulin dose requirements will change towards the end of life

Type 1 diabetes	Type 2 diabetes
Insulin absolutely essential. No endogenous supply	May have residual endogenous insulin secretion
Do not stop insulin in individuals with Type 1 diabetes	Many individuals with Type 2 Diabetes do not require insulin
Risk of DKA	Risk of HHS and DKA if ongoing blood glucose levels are too high
Hypoglycaemia risk will need to be reassessed with changes in eating patterns and with weight loss	Hypoglycaemia risk will need to be reassessed with changes in eating patterns and with weight loss
The simplest regimen should be chosen. Once or twice daily injection can be considered	The simplest regimen should be chosen if switching to insulin only. Both once or twice daily injection can be considered
A change of insulin regimen may be needed to match changes in activity levels	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	Equipment for insulin delivery may need to be reassessed if physical capabilities alter, vision is poor, or carers become involved in giving insulin
Doses may need to change with changes in renal function including those on renal replacement therapy	Doses may need to change with changes in renal function, including those on renal replacement therapy
Blood glucose monitoring will be individualised and reduced to once daily or pre administration of insulin to ensure glucose is within target range avoiding hypoglycaemia	Blood glucose monitoring will be reduced to a minimum and stopped completely if possible

**It is important to know what type of diabetes the individual has in order to** provide best advice in terms of insulin management as end of life approaches. Insulin dose requirements will change at this time.

# 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. Insulin pump users frequently perform capillary blood glucose tests and adjust insulin bolus doses according to the carbohydrate content of their food. This technology offers flexibility to respond to the changing insulin requirements towards end of life, providing the individual or carers have the skills and support to use it. If the person is an inpatient, please refer to local hospital policy for insulin pump use.

Individuals will need advice about the likely impact of their condition on their diabetes, so early involvement of the diabetes team is desirable. Avoidance of hypoglycaemia & hyperglycaemia with emphasis on less stringent blood glucose control is required. A range of basal insulin profiles may need adjustment in anticipation of changing insulin requirements. Mealtime and correction boluses will need to be adjusted to reflect predictable changes in insulin sensitivity, and to address the effects of diminishing appetite.

Consider with patient's changing condition:

- Basal and bolus insulin requirement may need to be adjusted regularly based on the person's changing condition and treatments.
- If at any time 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.

## Continuous blood glucose monitoring

Continuous glucose monitoring (CGM) may be used in conjunction with Insulin pumps (sensor augmented pumps) or as stand-alone CGM. The sensor augmented pump has a low glucose alarm or low glucose insulin suspend function. This is an additional safety feature that reduces the risk of hypoglycaemia. Patients with such technology should continue to use it providing that they and their carers are prepared to perform the necessary calibration of capillary blood glucose tests. Even in the last days of life when the person 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 team in their chosen place of care. For the inpatient setting please refer to local policy on insulin pump/CGM management.

## Flash glucose monitoring

FreeStyle Libre® flash glucose monitoring is a pre-calibrated sensor that measures the interstitial glucose concentration repeatedly for two weeks. Latest glucose concentration and trend directions are obtained by scanning the sensor with a reader. There is a lag time of 5 minutes between readings from flash glucose monitoring and capillary glucose levels. For the inpatient setting please refer to local policy on blood glucose monitoring.

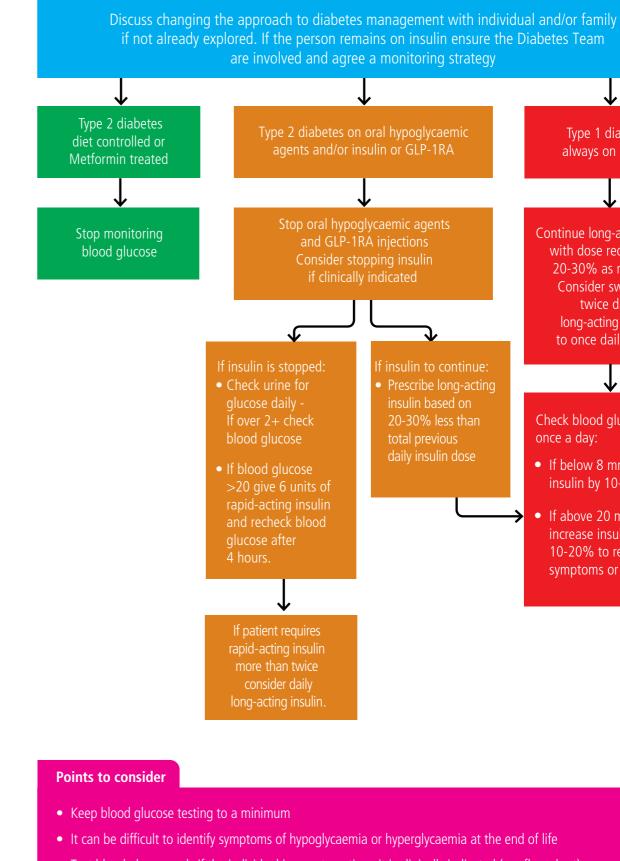
# FINAL DAYS / TERMINAL CARE

As patients approach the end of life, management of their diabetes becomes less about meeting blood glucose targets and more about the overall guality of life, where the patient wants to be and who they want around them.

If the patient is in hospital, there should be frank discussion about where they wish to be for end of life care, and if they want to go home everything possible should be done to facilitate this, provided their family or carers are in agreement and able to provide appropriate care. Such discussions may include resuscitation status and ceilings of care, and the outcome of these discussions should be clearly documented.

If the patient is at home, there should be some discussion with the patient about what should happen in the event of deterioration that might normally result in hospital admission, with a view to making a clear plan of care, and avoidance of hospital admission if this is the patient's wish. The specialist palliative care team will often take the lead on such discussions, but any member of the healthcare team who has a good relationship with the patient and family can do this.

Most medications, apart from essential drugs such as antiemetics and analgesics, can be stopped at this stage. Ideally by this time diabetes treatment has been minimised so that few changes are needed in the last days of life. The recommended blood glucose targets of 6-15mmol/l can often be relaxed further in the last few days of life, for example to targets of 10-20mmol/l, with reduced blood sugar monitoring and simplification of treatment regimens. At this time, most patients with type 2 diabetes can come off their diabetes treatments and stop blood glucose monitoring altogether, while those with type 1 diabetes will still need some insulin, but at significantly lower doses than before, and should require only once daily blood glucose monitoring.



- Flash glucose monitoring may be useful to avoid finger prick testing



# FLOW CHART FOR DIABETES CARE AT END OF LIFE<sup>1</sup>

f insulin to continue: • Prescribe long-acting insulin based on 20-30% less than total previous daily insulin dose

Type 1 diabetes always on insulin

Continue long-acting insulin with dose reduction of 20-30% as required. Consider switching twice daily long-acting insulin to once daily dosing

Check blood alucose once a day:

- If below 8 mmol/l reduce insulin by 10-20%
- If above 20 mmol/l increase insulin by 10-20% to reduce risk of symptoms or ketosis

• Test blood glucose only if the individual is symptomatic or it is clinically indicated (see flow chart)

# STEROID THERAPY

The use of glucocorticoid treatment in people with diabetes will frequently result in hyperglycaemic symptoms, which is a challenge. This may warrant temporary additional and more active glycaemic management. Regardless of the indication, steroid use can have an impact on blood glucose levels.

Short courses of steroid use (3 Days) resulting in hyperglycaemia may not warrant intervention. However, high dose steroids for longer periods may result in symptomatic hyperglycaemia including fatigue, polyuria and polydipsia with the real potential for acute complications such as HHS or the need for urgent insulin initiation.

- Steroid induced hyperglycaemia use of steroids in people with pre-existing diabetes resulting in deterioration of blood glucose control.
- Steroid induced diabetes a rise in blood glucose levels when taking steroids without a known diagnosis of diabetes. This may not resolve when the steroids are withdrawn.

## Steroid Therapy – impact on blood glucose

There are various steroid treatment regimens.

- Review timing of steroids and avoid administration after lunch where possible.
- Oral administration of steroids in the morning usually gives rise to elevated blood glucose levels by late morning that can continue into the evening. The blood glucose level rises approximately 4-8 hours after administration. However, be mindful that overnight the blood glucose level tends to fall back to baseline fasting levels. The treatment should be tailored to treat hyperglycaemia while avoiding nocturnal and early morning hypoglycaemia.
- Intravenous steroids cause a guicker and more sustained elevation in blood glucose levels.
- Blood glucose levels may return to pre steroid levels within 24 hours after stopping intravenous steroids.
- If oral steroids are going to be weaned down over a period of days or weeks the blood glucose levels may reduce in a dose dependant fashion.

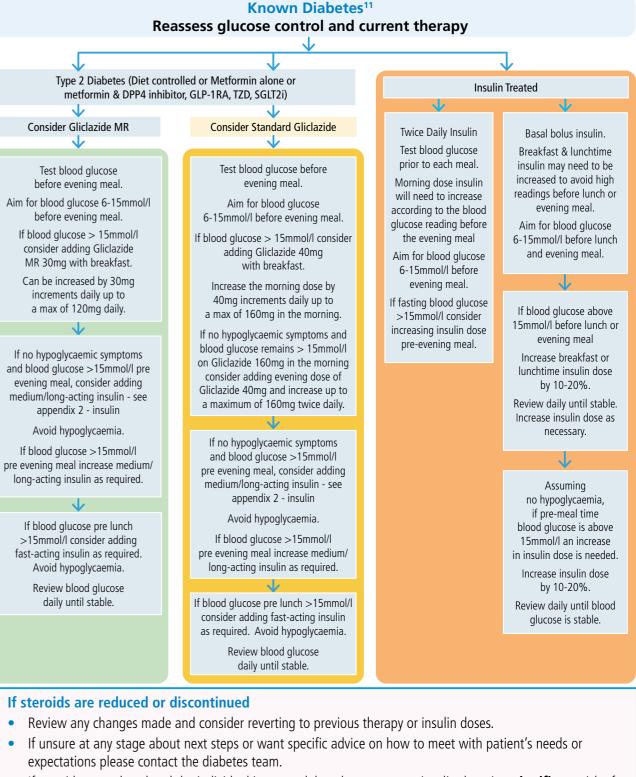
### Commonly used Oral and Intravenous Steroids with duration of action

Steroid	Doses orally	Doses Intravenously	Duration of action
Hydrocortisone	10-20mg	100mg up to QDS	8-12 hours
Prednisolone	5mg and upwards	N/A	16-36 hours
Dexamethasone	0.5mg-16mg OD/BD	4-16mg OD/BD	36-54 hours

## Algorithm for managing hyperglycaemia secondary to steroid therapy

### **No Known Diabetes**

- Check random blood glucose before starting on steroids to identify individuals at risk.
- Impaired Fasting Glucose (IFG) = fasting plasma glucose (FPG) 5.6 6.9mmol/l
- Impaired Glucose Tolerance (IGT) = blood glucose 7.0 11.0mmol/l or HbA1c 39 47mmol/mol.
- Diabetes = FPG  $\ge$  7.0mmol/l or HbA1c 48mmol/mol or above<sup>10</sup>. •
- Elevated blood glucose should be managed as Type 2 Diabetes below.



hypoglycaemia. Please reduce the dose of these drugs in tandem with the steroid dose reduction

• If steroids are reduced and the individual is on a sulphonylurea agent or insulin there is a significant risk of

# HYPOGLYCAEMIA

It is particularly important to recognise signs and symptoms of hypoglycaemia (<4mmol/l)<sup>12</sup> and treat appropriately. You may need to stop hypo-inducing blood glucose lowering treatment at this time, whether the patient is at home or in hospital. Patients who are imminently dying may have blood glucose <4mmol/l and may have asymptomatic hypoglycaemia which may not require treatment.

## Hypoglycaemia Management

Hypoglycaemia can be troublesome at any time in individuals with diabetes. Every effort should be made to avoid this at the end of life.

- Agree a care plan and glucose targets
- Tailor insulin therapy and avoid insulin dose errors
- Other factors/steps that should be considered are:
  - Rationalisation of glucose-lowering treatment for diabetes
  - Involve a community dietitian
  - Early identification of risk factors for hypoglycaemia
  - Person with hypoglycaemia unawareness
  - Treat pain effectively
  - Assess impact of weight loss
  - Assess influence of nutritional deficits
  - Assess influence of opiates/other pain killers on appetite

## Identifying those at risk:

These include all insulin preparations, sulphonylurea (e.g. Gliclazide, Glipizide, Glimepiride) and glinides (Repaglinide). Individuals who are at particularly 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
- Individual with previous hypoglycaemia
- Nausea and vomiting
- Previous gastrectomy
- Frailty
- Cognitive impairment

## Identifying hypoglycaemia: signs and symptoms:

- Sudden onset of hunger
- Sweating
- Palpitations/feeling anxious
- Feeling "jittery"
- Tingling in lips
- Feeling dizzy or faint
- Feeling confused or finding it difficult to concentrate
- Patient may look pale, become confused, have behaviour changes, become very drowsy, and lose consciousness. Sweating, fits, and skin colour changes 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.





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

# HYPOGLYCAEMIA

Sick day management for use in individuals who may have an intercurrent illness or **be unwell** as a result of side effects of chemotherapy

## Never discontinue long-acting insulin

## **General advice**

- 1. If unable to eat usual meals keep hydrated Offer sips of sugar free fluids (aim for 100mls /hour)
- 2. Offer frequent small portions of easily digested foods eq soup, ice cream, yoghurt, custard, flat 7up
- 3. Check blood glucose and ketones every 2-4 hours
- 4. If ketones are high, extra insulin is needed
- 5. Aim for blood glucose levels between 6 and 15mmol/l
- 6. If blood glucose < 4 mmol/l please refer to hypoglycaemia guideline (pp19-20)

## If individual has hyperglycaemia (blood glucose >15mmol/l)

- 1. Test for blood/urinary ketones as per local guidance
- 2. If blood glucose is >15 mmol/l, without elevated ketones, consider giving a correctional dose of rapid-acting insulin (Novorapid, Apidra, Humalog, Fiasp) to achieve blood glucose target of <15 mmol/l.

### 1 unit of rapid-acting insulin will usually lower blood glucose by approximately 2-3 mmol/l over 2-4 hours.

Blood ketone level	Urine ketone level	Interpretation <sup>13</sup>
Below 0.6mmol/l	+1	This is normal for the person with diabetes. If blood glucose is >15mmol/l treat hyperglycaemia.
0.6-1.5mmol/l	+2	Moderate ketones are present. This indicates a need for extra insulin. Consider increasing insulin doses / carbohydrate intake and recheck blood glucose and ketone levels every 1-2 hours. At risk of Diabetic ketoacidosis (DKA)
More than 1.5mmol/l	+3	Large ketones are present. Extra insulin is required. At risk of DKA. Contact the diabetes team. Re-check blood glucose and ketone levels every 1-2 hours Continue usual <b>fast-acting insulin</b> dose with meals. Give additional 10% of total daily insulin dose <sup>#</sup> as <b>fast-acting</b> <b>insulin</b> every 2 hours until ketones <1.5mmol/l as per hospital policy.
More than 3mmol/l	More than 3	Ketoacidosis is posing an immediate threat to health. Summon diabetes team for assistance immediately. Continue usual <b>fast-acting insulin</b> dose with meals. Give additional 20% of total daily insulin dose <sup>#</sup> as <b>fast-acting</b> <b>insulin</b> every 2 hours until ketones <1.5mmol/l as per hospital policy.

Total daily insulin dose calculation: Add up total amount of insulin administered in previous 24 hours # adapted from Sligo University Hospital

# Sick Day Management for people with Type 2 Diabetes<sup>1</sup>

Sick day management for use in individuals who may have an intercurrent illness or **be unwell** as a result of side effects of chemotherapy

## Individuals should continue to take their regular diabetes medications provided they are eating and drinking normally

## **General advice**

- 1. If unable to eat usual meals keep hydrated Offer sips of sugar free fluids (aim for 100mls/hour)
- 2. Offer frequent small portions of easily digested foods eg soup, ice-cream, yoghurt, custard, flat 7-up.
- 3. Check blood glucose 4 hourly.
- 4. Aim to maintain blood glucose levels at 6-15mmol/l.
- 5. Contact the diabetes team if the individual has persistent vomiting and is unable to keep diet/fluids down.
- 6. Consider increasing diabetes medications/ insulin if blood glucose >15mmol/l
- 7. Consider adding insulin if individual on maximum dose of oral hypoglycaemic agents and blood glucose >15mmol/l
- 8. Consider reducing/ discontinuing diabetes medications if blood glucose <6mmol/l and individual is not eating
- 9. Gradually reduce the adjustments made as illness improves.

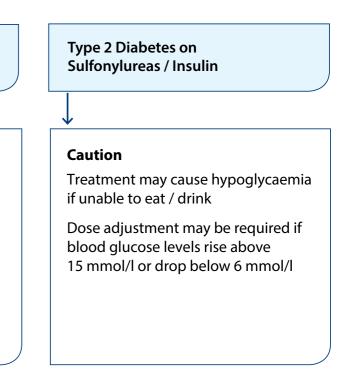
## Type 2 Diabetes on oral hypoglycaemic agents / GLP-1 agonists

## Caution

Metformin / SGLT2 inhibitors / GLP1 agonists can contribute to dehydration in the presence of nausea / vomiting

**Stop** Metformin and SGLT2 inhibitors in acute illness

Consider stopping GLP-1Agonists



# **NUTRITION**

## Introduction

Nutrition and hydration are basic human needs. However, as a patient enters the end of life phase their longing for foods and fluids can significantly decrease. It would be preferable to discuss the risks and benefits of options for nutrition and hydration with the person who is approaching death or their family / next of kin, to allow their wishes to be taken into account. In general the first option for nutrition and hydration is the oral route. However if an individual is unable to consume food or fluids safely other artificial options may need to be explored. It



is acknowledged in NICE guidelines that clinically assisted hydration may ease some distressing symptoms caused by dehydration but additionally could have adverse consequences e.g. fluid overload<sup>14</sup>.

## **Swallowing Issues and Poor Appetite**

Patients with diabetes presenting with poor appetite or swallowing issues can pose as a concern due to the significant impact reduced meal size can have on blood glucose levels. Limiting high fat and free sugars may no longer be appropriate if a patient's food choices become limited and patients may benefit from medical management of their diabetes around their new dietary patterns.

Support from a dietitian regarding appropriate food choices based on a patient's overall condition can be very beneficial at this stage. It is not uncommon that this patient group would be advised to follow a high energy, high protein diet to help minimise loss of lean muscle mass. This comprises energy and protein dense meals and snacks, and may affect the patient's glycaemic control. It would be an ideal scenario to aim for optimal intakes without compromising discomfort due to symptoms of uncontrolled blood glucose levels e.g. increased thirst, urination, fatigue, thrush etc.

Ideally, to avoid limiting diet it would be preferable for medications to be adjusted in line with meal size and frequency. Consider asking a pharmacist or clinician to review medication with regard to availability of liquid or alternative formulations, alternative routes of administration or advice on the suitability of crushing a medication. For example, gliclazide MR tablets are modified release and cannot be crushed (option to switch to standard release gliclazide). Clinicians should consider some of the following points regarding medication adjustments in this specific patient group:

- Liquid medications e.g. Metformin in solution form should be considered for patients unable to manage tablets.
- If smaller meals are being consumed it would be preferable to avoid long-acting sulphonylurea preparations e.g. Gliclazide, or Glimepiride.
- For patients managing small, regular meals Repaglinide can be useful. This should only be taken with meals.
- If blood glucose levels remain high despite small oral intakes, a low-dose insulin may be required.
- Patients who are on insulin and have reduced oral intakes may require reduced insulin dose<sup>15</sup>.

## **Enteral Feeding**

The current evidence about the benefits, burdens and risks of artificial nutrition as patients approach the end of life is not clear-cut<sup>14</sup>. As an individual approaches end of life the main focus should be guality of life and guality of death as opposed to length of life. Alternative methods of feeding such as enteral nutrition may be considered in patients who are unable to meet their nutritional needs via the oral route. However, it should be noted that losing the ability to swallow can be part of the dying process and in most instances artificial nutrition and hydration are not appropriate<sup>15</sup>.

When considering artificial nutrition for patients with diabetes at the end of life phase, the aims of treatment should revolve around:

- Providing adequate/ appropriate nutrition
- Patient safety i.e. avoiding hypoglycaemia
- Managing symptoms related to hyperglycaemia

A feeding regime should be put in place, following an assessment from a dietitian. This will include appropriate macronutrient and micronutrient amounts based on individual patient needs.

The team should liaise with dietitians and pharmacists, when prescribing diabetic medications for tube fed patients. As most oral hypoglycaemic agents are not available in liquid form, considerations must be made on the appropriate medication changes required, to best suit a patient's needs.

Some considerations must be made for patients on insulin therapy while on enteral feeds. The type of insulin required will depend on the enteral feed content, duration and frequency of feeds being provided, to optimise glycaemic control.

**Continuous Feeding-** e.g. feeding for a set period of time without break e.g. over-night feeding, may require intermediate insulin given at the beginning of the feed or alternatively a mixture of intermediate and fast-acting insulin may be given at the beginning of the feed and half-way through.

**Bolus Feeding-** e.g. feeding for shorter periods at multiple points throughout the day, may require a fast-acting insulin at the beginning of every feed. Basal insulin may also be required. Note: Ensure there is a 4 hour gap between each bolus if considering fast-acting insulin for each bolus.

Continuous feeding with regular/ ad-hoc meals- an intermediate or long acting insulin should be provided at the beginning of feeds. A fast-acting insulin should be considered with each meal or supplementary feed consumed<sup>1</sup>.

## Managing Hypoglycaemia in Enterally Fed Patients

If a patient on an enteral feed experiences hypoglycaemia during or after the feed, certain measures should be taken to manage the episode, while also aiming to prevent further incidences of hypoglycaemia. It is recommended that a 15g fast-acting carbohydrate hypo treatment e.g. LIFT<sup>™</sup> (formerly known as Glucojuice) should be given via the enteral feeding tube and the tube feed should be continued. Blood glucose level checks should be repeated after 10-15 minutes and hypo treatment may be repeated if blood glucose levels remain <4mmol/L. In the event that hypoglycaemia has occurred while the tube feed is not currently running, or is not due to start within 30 minutes, approximately 75ml bolus of Ensure Compact (or approximately 20g carbohydrate equivalent of another sip feed) should be given, after being first treated with LIFT™ and when blood glucose levels have risen to >4mmol/L. Possible causes of hypoglycaemia should be explored e.g. blocked tube, malabsorption, vomiting, incorrect timing of insulin etc. and a reduction in insulin dose should be considered by the team if appropriate / required<sup>16</sup>.

## Conclusion

It is important to note that the purpose of food does not lie fully with nutrition. Eating can play an important part in social interaction, enjoyment, celebrations, hospitality and nurture. Individuals who are unable to eat normally, can miss out on these benefits. In addition to this, food also plays a huge role in the self-management of diabetes. Therefore, this loss of control, choice and enjoyment of eating can lead to a host of complex issues that should be kept in consideration. A good communication pathway with the full multidisciplinary team, patient and family members, is an integral part of managing this complex patient group and therefore, clear goals / aims of treatment should be agreed upon on an individual patient basis.

# ADVANCE HEALTHCARE PLANNING

For people with diabetes towards the end of life, effective care planning needs to include decisions about future care. The patient's wishes are paramount and the views of family and carers should be considered, especially where the patient is unable to express his or her own wishes. The multidisciplinary care team should document the outcome of such discussions.

These discussions are often triggered by a marked deterioration in the individual's functional status or the development of medical complications which may result in a shortening of the individual's prognosis to a few weeks - however, effective care planning occurs when important decisions about future treatments or overall healthcare are taken at a much earlier stage.

The Assisted Decision-Making (Capacity) Act (ADMA) 2015<sup>17</sup>, when it is implemented, will allow an adult to make a legally binding statement known as an Advance Healthcare Directive at a time when they have full mental capacity. This will allow people to refuse any form of treatment, including life-sustaining treatment. This Directive comes into effect if an adult loses capacity at some time in the future and is unable to make treatment decisions for themselves.

## Some key points about Advance Healthcare Directives:

- 1. Advance Healthcare Directives have been recognised in common law for some time but the Act provides for a legislative framework.
- 2. Under the new provision, a person aged 18 and over who has capacity can prepare an Advance Healthcare Directive.
- 3. They must put their decisions on future medical treatment in writing and their Advance Healthcare Directive must be witnessed.
- 4. A person can revoke an Advance Healthcare Directive at any time providing the person still has capacity to do so. This must be done in writing.
- 5. No one can be forced to create an Advance Healthcare Directive.
- 6. Having witnesses to the Advance Healthcare Directive is designed to prevent people being forced to make certain decisions.
- 7. A person making an Advanced Healthcare Directive can nominate people who will be legally recognised as acting on their behalf at a time when they lose capacity and can ensure their Advance Healthcare Directive is enforced.
- 8. An Advance Healthcare Directive only comes into force when the person has lost capacity and cannot make a decision.
- 9. Having an Advance Healthcare Directive helps healthcare professionals in caring for patients the way they want.
- 10. Having an Advance Healthcare Directive helps families as it removes doubt about what care their loved one would have wanted.
- **11.** If there is any doubt about an Advance Healthcare Directive, a person can go to the courts.

The Irish Hospice Foundation has very useful information about Advance Care Planning.

This is available on its website (https://hospicefoundation.ie/programmes/advance-care/).

It includes the following:

- Update on Advance Care Planning (IHF guidance document)
- Information on The Think Ahead programme, which includes an Advance Healthcare Directive that is compliant with the legislation
- The Support and Advocacy Service for Older People (SAGE) guides and information
- Law Reform Commission reports on vulnerable adults and the law and on Advance Healthcare Directives
- Medical and Nursing codes of conduct and ethics

# SUMMARY OF CLINICAL CARE **RECOMMENDATIONS FOR END OF LIFE CARE**

These clinical care recommendations emphasise the following:

- Early identification and support for patients approaching end of life.
- The need to balance benefits of diabetes interventions with prognosis.
- Patients and families / carers should be involved in decisions about diabetes management.
- Diabetes management requirements can change quickly with steroid use, weight loss, liver or renal disease.
- The diabetes team should be involved, when necessary, in the care of the patient approaching end of life.
- Interventions and monitoring should be kept to a minimum as end of life approaches, with the aim of keeping the patient comfortable without compromising safety (i.e Avoid DKA, symptomatic hyperglycaemia and hypoglycaemia).

# **REFERENCES AND RESOURCES**

- 1. Diabetes UK. End of Life Diabetes Care, Clinical Care Recommendations. 2018 (3rd Edition). Available at: https://www.diabetes.org.uk/resources-s3/2018-03/EoL\_Guidance\_2018\_Final.pdf (accessed 20th November 2020)
- 2. International Diabetes Federation. IDF Atlas. 2019 (ninth edition). Available at: www.idf.org/e library/epidemiology-research/diabetes-atlas/159-idf-diabetes-atlas-ninth-edition-2019.html accessed 20th November 2020)
- 3. Irish Hospice Association website [Online]. Available at: www.hospicefoundation.ie/aboutus hospice-palliative-and-end-of-life-care/definitions (Accessed 17th November 2020)
- 4. General Medical Council (2010) Treatment and care towards the end of life: good practice in decision making. Available at: www.gmc-uk.org/-/media/documents/treatment-and-care-towards the-end-of-life---english-1015 pdf-48902105.pdf
- 5. 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. 2016. Available at: https://www.goldstandardsframework org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17 pdf (Accessed 17th November 2020)
- 6. Medicines information online. Available at: www.medicines.ie (Accessed 16th November 2020)
- 7. Health Products Regulatory Authority website. Available at: https://www.hpra.ie/homepage medicines(Accessed 19th November 2020)
- 8. Joint British Diabetes Societies Inpatient Care Group (2013) The Management of Diabetic Ketoacidosis in Adults (JBDS 02). Available at: https://abcd.care/sites/abcd.care/files resources/2013\_09\_JBDS\_IP\_DKA\_Adults\_Revised.pdf
- 9. Peters A, Buschur, Buse J, Cohan P, Diner J, Hirsch I. Euglycaemic Diabetic Ketoacidosis: A Potential Complication of Treatment With Sodium-Glucose Cotransporter 2 inhibition. Diabetes Care. 2015; 38(9):1687-1693. Available at https://care.diabetesjournals.org/content/38/9/1687 (Accessed 19th November 2020)
- 10. American Diabetes Association. Classification and Diagnosis of Diabetes: Standards of Medical Care in Diabetes. Diabetes Care 2020; 43 (Suppl. 1): S14 - S31. Available at https://care.diabetesjournals org/content/43/Supplement\_1 (Accessed 17th November 2020)
- **11.** Joint British Diabetes Societies (2021) Management of Hyperglycaemia and Steroid (Glucocorticoid) Therapy (JBDS 08). Available at https://abcd.care/sites/abcd.care/files/site\_uploads/JBDS\_08 Steroids\_DM\_Guideline\_FINAL\_28052021.pdf
- **12.** Joint British Diabetes Societies (2021) The Hospital Management of Hypoglycaemia in Adults with Diabetes Mellitus (JBDS 01). Available at: https://abcd.care/sites/abcd.care/files/site uploads JBDS 01 Hypo Guideline FINAL 23042021 0.pdf
- 13. Abbott Diabetes Care website (online) Ketone testing. Available at: https://freestylediabetes.ie managing-and-monitoring/ketone-testing. (Accessed 17th November 2020)
- 14. National Institute of Health and Care Excellence (NICE) Care of dying adults in the last days of life. 2017. Available at:www.nice.org.uk/guidance/ng31. (Accessed 24th November 2020)
- 15. Irish Hospice Foundation. Palliative Care for the Person with Dementia Guidance Document 4 - Management of Hydration and Nutrition. 2016 Available at:www.hospicefoundation.ie/wp content/uploads/2016/11/Final-Guidance-Document-4-Nutrition-and-Hydration-1.pdf (Accessed 24th November 2020)
- 16. Worcestershire Acute Hospitals NHS Trust. WAHT-END-009. Guideline for Enteral Tube Feeding (Nasogastric of PEG) in Patients with Diabetes Mellitus Treated with Insulin. 2015. Available at http://www.treatmentpathways.worcsacute.nhs.uk/EasysiteWeb/getresourceaxd? AssetID=156391&servicetype=Attachment(Accessed 24th November 2020)
- 17. Irish Statute Book (Office of the Attorney General). The assisted Decision making (Capacity) Act ADMA). 2015. Available at http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html (Accessed 17th November 2020)

# **REFERENCES AND RESOURCES**

### **Bibliography:**

Harkins V, Irish College of General Practitioners (2016) A Practical Guide to Integrated Type 2 Diabetes Care www.hse.ie/eng/services/list/2/primarycare/east-coast-diabetes-service/management-of-type-2diabetes/diabetes-and-pregnancy/icgp-guide-to-integrated-type-2.pdf

www.diabetes.ie/wp-content/uploads/2018/06/NCG-No-17-Adult-T1-DM\_-Web-ready-copy-1.pdf

Health Services Executive (2015) Model of Care for All Children and Young Adults with Type 1 Diabetes. Available from: https://www.diabetes.ie/wp-content/uploads/2015/12/National-Clinical-Programmefor-Diabetes-and-Paediatrics.pdf.

American Diabetes Association. Standards of Medical Care in Diabetes – 2020. Diabetes Care 2020 Jan; 43 (S 1-212) https://care-diabetesjournals-org.eu1.proxy.openathens.net/content/43/Supplement\_1

National Institute of Clinical Excellence (NICE). Type 1 diabetes in adults: diagnosis and management. 2016 (updated) www.nice.org.uk/guidance/ng17

www.nice.org.uk/guidance/ng28

Sinclair AJ, Dunning T. Clinical Guidelines for Type 1 Diabetes Mellitus with an Emphasis on Older Adults. 2019. www.diabetes.org.uk/resources-s3/2019-05/Clinical%20Guideline%20for%20Type%201%20 Diabetes%20for%20Older%20Adults%20-%20April%202019.pdf

## **Useful Websites:**

Irish Hospice Foundation www.hospicefoundation.ie

All Ireland Institute of Hospice and Palliative Care www.aiihpc.org

Diabetes Ireland www.diabetes.ie

National Clinical Programme for Palliative Care www.hse.ie/eng/about/who/cspd/ncps/palliative-care

National Clinical Programme for Diabetes www.hse.ie/eng/about/who/cspd/ncps/diabetes

Irish Cancer Society www.cancer.ie

Irish Association for Palliative Care www.iapc.ie

Care Alliance Ireland www.carealliance.ie

Hospice UK https://www.hospiceuk.org

Diabetes UK www.diabetes.org.uk

American Diabetic Association www.professional.diabetes.org

UK Gold Standards Framework www.goldstandardsframework.org.uk

Association of British Clinical Diabetologists (resources including guidelines for inpatient care) www.abcd.care

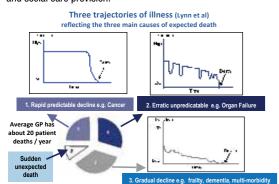
Trend-DIABETES (resources including Hypo, Illness, and Steroid Leaflets - Log-in required) www.trenddiabetes.online

- Department of Health (2018) Adult type 1 diabetes mellitus, National Clinical Guideline No. 17 https://
- National Institute of Clinical Excellence (NICE). Type 2 diabetes in adults: management. 2019 (updated)

- The Palliative Hub An All Ireland Gateway to Palliative Care Information www.thepalliativehub.com

# **APPENDIX 1 - GOLD STANDARDS FRAMEWORK**

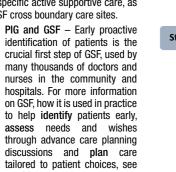
#### $\langle \rangle$ The Gold Standards Framework Royal College of the gold standards General Practitioners framework Proactive Identification Guidance (PIG) The National GSF Centre's quidance for clinicians to support earlier identification of patients nearing the end of life leading to improved proactive 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 National Policy support for earlier identification. patients earlier. General Medical Council – 2010 This updated 6th edition of the GSF PIG. renamed as Proactive www.gmc-uk.org/static/documents/content/End\_of\_life.pdf 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 hours or days) and those with: trajectories of illness for expected deaths - rapid predictable decline Advanced, progressive, incurable conditions. e.g. cancer, erratic decline e.g. organ failure and gradual decline e.g. · General frailty and co-existing conditions that mean they are expected frailty and dementia. Additional contributing factors when considering to die within 12 months. prediction of likely needs include current mental health. co-morbidities and social care provision.



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

Earlier identification of people who may be in their final stage of life leads to more proactive person-centred care. About 1% of the population die each vear, 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 ne Plan living well and dving well the GSF website.



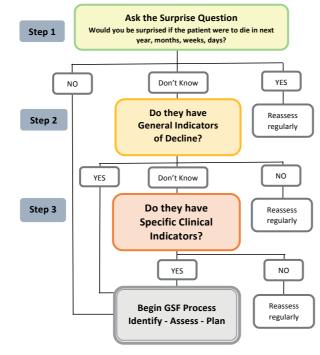
The GMC definition of End of Life Care; 'People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few

- · Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- · Life threatening acute conditions caused by sudden catastrophic events.'

#### NICE Guidance in End of life care 2011 Quality statement 1 https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-1-Identification

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

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



The GSF Proactive Identification Guidance (PIG) 2016 vs6 © The Gold Standards Framework Centre in End of Life Care For more information on the development of the GSF PIG, its use in practice, evidence base, applications and when referencing it, please refer to www.goldstandardsframework.org.uk/PIG 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 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% 1vr mortality). · Difficult ongoing physical or psychological symptoms despite optimal tolerated therapy.
- Additional features include hyponatraemia <135mmol/l. high BP. declining renal</li> 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.

- 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
- Beneated 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

#### iver Disease

- lepatocellular carcinoma.
- Liver transplant contra indicated Advanced cirrhosis with complications including:

• Fulfils long term oxygen therapy criteria (Pa02<7.3kPa). Required ITU/NIV during hospital admission

### 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

#### 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
- 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.
- Dvsphagia + poor nutritional status.
- Communication difficulties e.g., Dysarthria + fatigue.
- Cognitive impairment notably the onset of deme.

### 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:

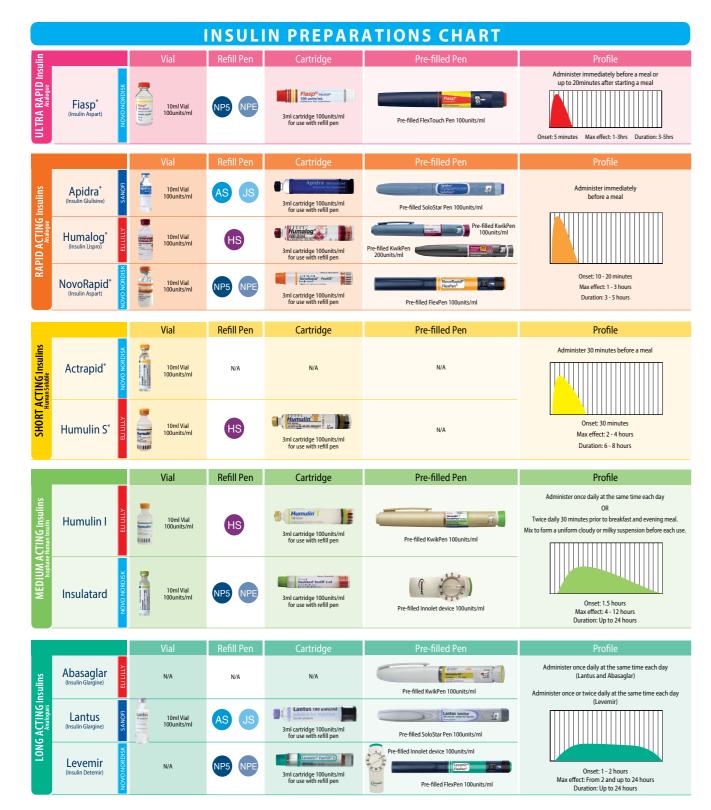
- Unable to walk without assistance and
- Urinary and faecal incontinence and
- No consistently meaninoful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score >3

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

### Stroke

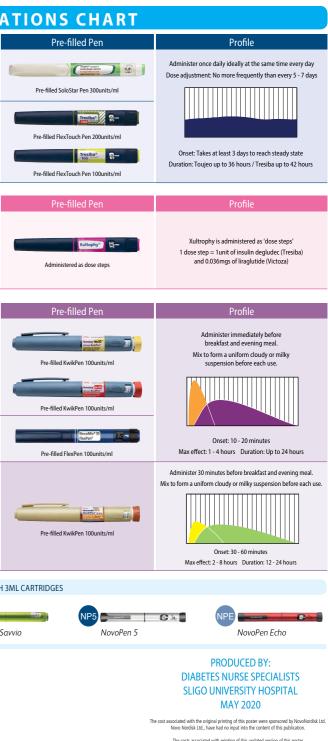
- Use of validated scale such as NIHSS recommended.
- Persistent vegetative minimal conscious state or dense paralysis
- Medical complications, or lack of improvement within 3 months of onset.
- Cognitive impairment / Post-stroke dementia.
- Other factors e.g. old age, male, heart disease, stroke sub-type,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

# **APPENDIX 2 - INSULIN**



					IN PREPARA	
LONGER ACTING Insulins	Toujeo	SANOFI	Vial	Refill Pen	Cartridge	
	(Insulin Glargine)	SAN			N/A	
	Tresiba (Insulin Degludec)	NOVO NORDISK	N/A	N/A	N/A	
		2				
<b>B</b> N N			Vial	Refill Pen	Cartridge	
LONGER ACTING Insulth Combo with GLP1	Xultophy ((Insulin Degludec/ Liraglutide))	NOVO NORDISK	N/A	N/A	NA	
			Vial	Refill Pen	Cartridge	
	Humalog Mix 25	ELILILY	N/A	HS	Amador Mar 25*	
ulins	Humalog Mix 50	פרו הוררא	N/A	HS	C C C C C C C C C C C C C C C C C C C	
<b>BIPHASIC Insulins</b>	NovoMix 30	NOVO NORDISK	N/A	NP5 NPE	Movemble <sup>®</sup> 30 Perrill <sup>®</sup> )	
BII	Humulin Humulin M3	פרו רוררא	10ml Vial 100units/ml	HS	Ministrice Constraints of the second	
					REFILL PENS FOR USE WITH	
AS AllSTAR pen JuniorSTAR pen HumaPen Sa						
	Γ.					
In ord		rors it	is recommended to presc	ribe all insulins using	their trade names.	
All Insuli All insuli Insulin p	n in use should have opening dat ens in use should be labelled with	e record 1 legible	led and not be in use for more than 4 we patient name and Hospital Number.	eeks.	room temperature in a locked drug trolley.	
Insulin sh	hould only be drawn up from a via	al using	sulins marked with an * may also be adr an insulin U100 syringe. Insulin MUST N For specific product instructions refer to	OT be drawn up from cartridge	es or disposable pens. ristics.	

oduct names, company names and logos appearing on this poster are registered and protected by their respective owner



The costs associated with printing of this updated version of this poster have been sponsored by the Irish Diabetes Nurses and Midwives Specialist Associatio

# NOTES

# NOTES

Diabetes Care Towards End of Life Clinical Care Recommendations 2021



Supported by an unrestricted educational grant from Novo Nordisk