Palliative and End of life Care

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Aims

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- Palliative Medicine symptom control – common problems
- Recognizing symptoms when someone is approaching the end of their life
- Future care planning – what needs to be considered relevant to pancreatic cancer

Defining terms

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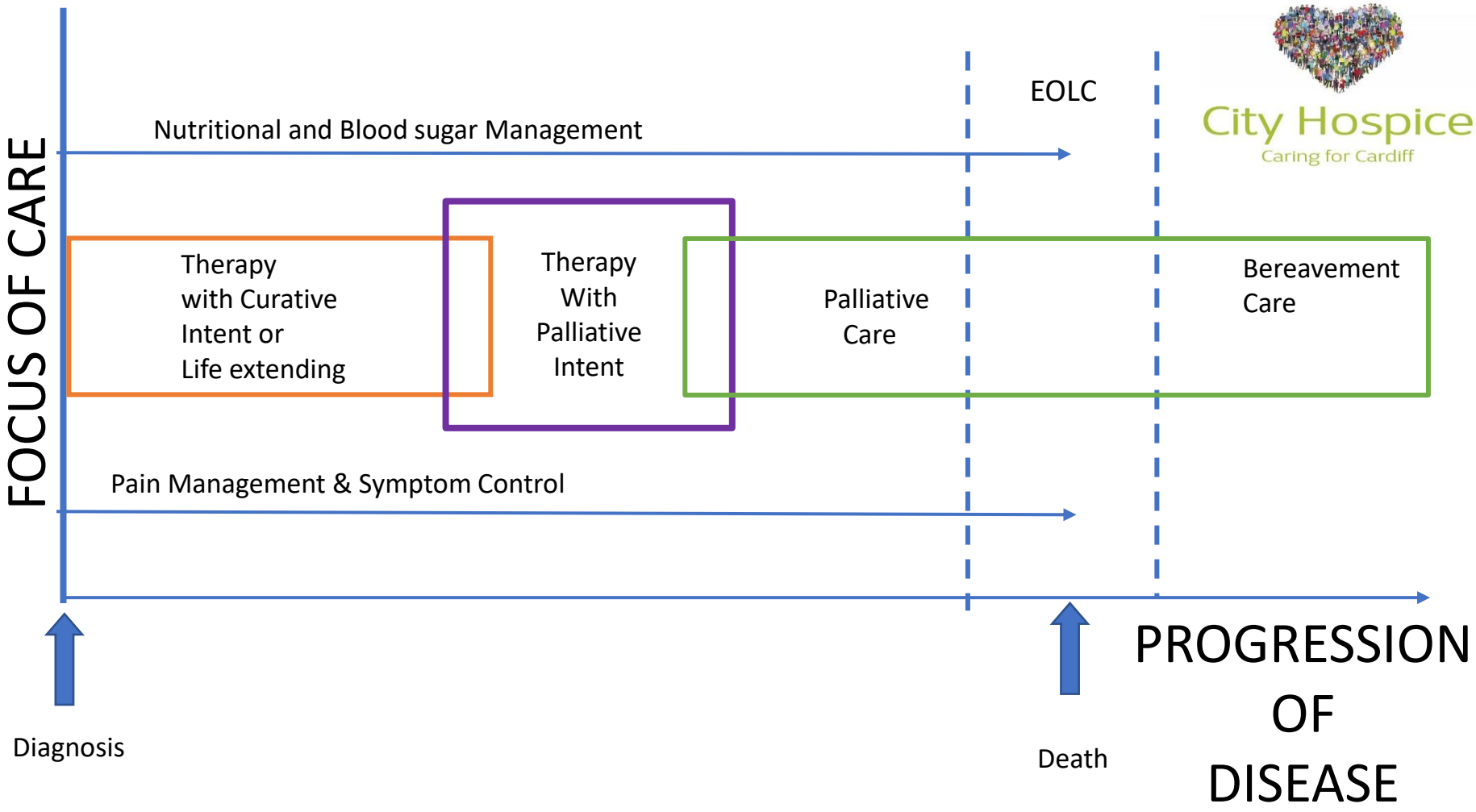
Palliative – a holistic and person-centred approach to improve the quality of life for patients and their families who are facing problems associated with a life-threatening illness

End-of-life Care (EoLC) – the provision of healthcare in the last weeks of someone's life. Typically, within the last 3-months of a person's life, they require increased support from healthcare professionals to manage physical, social and psychological support needs


FOCUS OF CARE
EOLC
Nutritional and Blood sugar Management
Therapy with Curative Intent or Life extending
Therapy With Palliative Intent
Palliative Care
Bereavement Care
Pain Management & Symptom Control
Diagnosis
Death
PROGRESSION OF DISEASE
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Yes, early Palliative Care is proven better... Like before it hits 4:30 on Friday!!

THE INK VESSEL

N. GRAY, MD

Pancreatic cancer

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- 5th commonest source of referrals to City Hospice
- UK stats: lowest survival rate of all common cancers
  - 5-year survival less than 7%
- In Wales 1-year survival 24.5%
- 3 in 5 people are diagnosed at an advanced stage
- 7 in 10 people with pancreatic cancer do not receive any active treatment
- Pancreatic cancer accounts for 7% of all cancer referrals to City Hospice

Case Study 1

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Clinical History

- Builder
- Returned from holiday
- Attended A&E abdominal pain

Investigations

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- Blood tests
- CT scan result
- ERCP and biopsy
- OPA result of scan
- Oncology plan
- Referred for palliative care

Palliative medicine assessment

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- Clarify understanding
- Communication
- Expectations
- Holistic assessment (physical, psychological, spiritual social)
- Symptoms (pain, GI, pancreatic function)
- Management plan for symptoms
- Introduce the concept of Future care planning

Communication

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- Relevance to all health professionals
- Establishing patients understanding
- Establish families understanding
- Correct misunderstanding
- Answer questions
- Consider implications
- Who to contact when?

Professional goals for consultation

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- Pain control – adjustments needed
- GI function
- Pancreatic function – consider PERT titration
- Psychological reaction/mood - monitoring
- Discussion around ‘what to do if health changes’
- Impact of oncology intervention - what are we looking to achieve?
- Discussion with family
- Future care planning – what are his priorities?

Steatorrhea

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- Very common in pancreatic cancer
- Excessive fat in faeces
- Difficult to flush
- May float/stick to sides of toilet pan
- PERT should be increased to improve fat absorption
- 95% of patients with Pancreatic Cancer will be prescribed PERT (Pancreatic Cancer, UK)

Person-centred care

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- Regular follow up
- Oral route for medication
- Titration of analgesia
- Laxatives/diarrhoea and constipation
- Anti-emetics & role of prokinetics
- Check Blood sugar
- PERT (+/- PPI)
- Appetite & weight loss
- Mood
- Exploration of his concerns and consider future care planning

Pain management for pancreatic cancer

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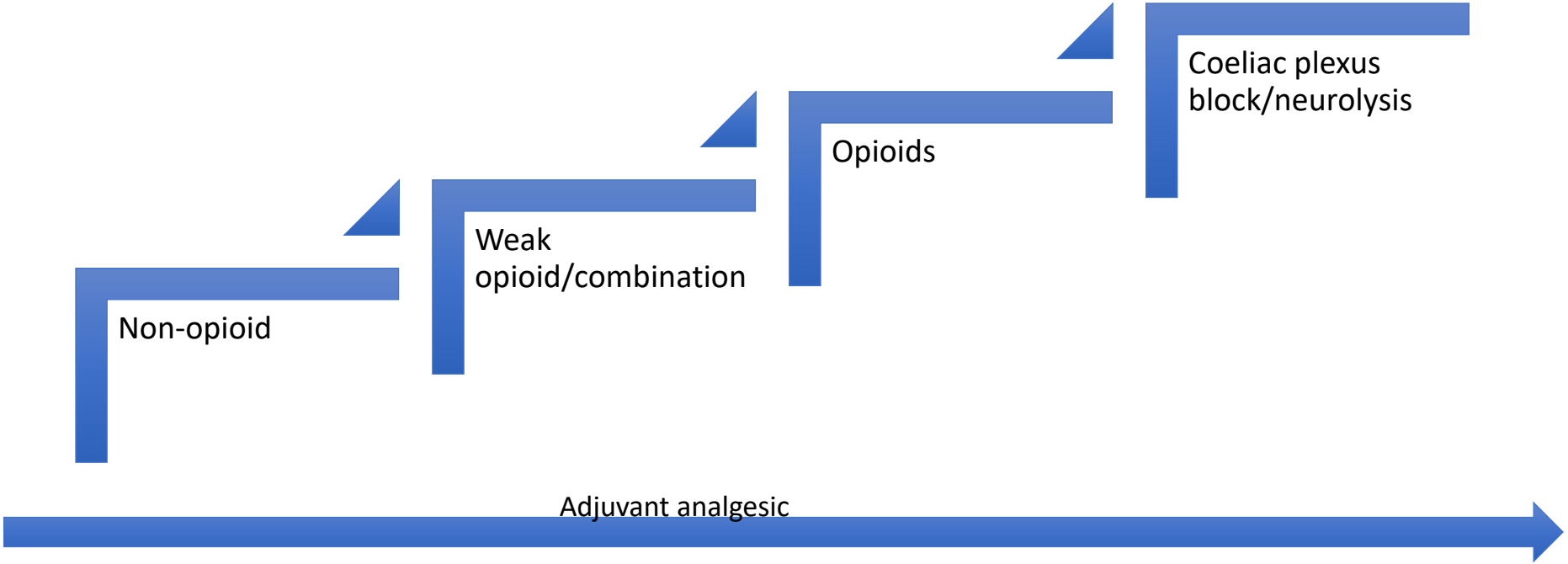

Pain management

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- Oral co-codamol 30/500 x2 QDS approximate to 24mg morphine
- Oramorph 5mls = 10mg QDS
- Total = ??

New dose of MST =……..

New dose of oramorph is always 1/6th

So the oramorph dose is…….

If unable to swallow morphine and we want to use subcutaneous route

CSCI/syringe driver equivalent is…….

Prn subcutanous breakthrough dose is…….

Nausea & vomiting

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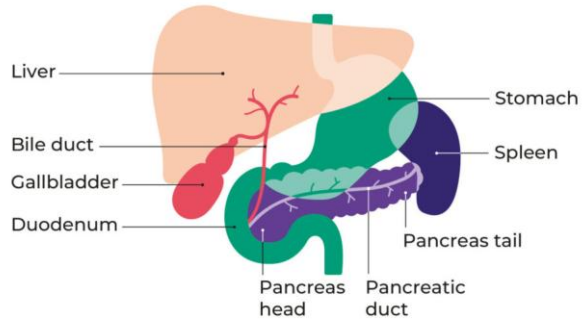
Early satiety, gastric stasis, nausea



Causes

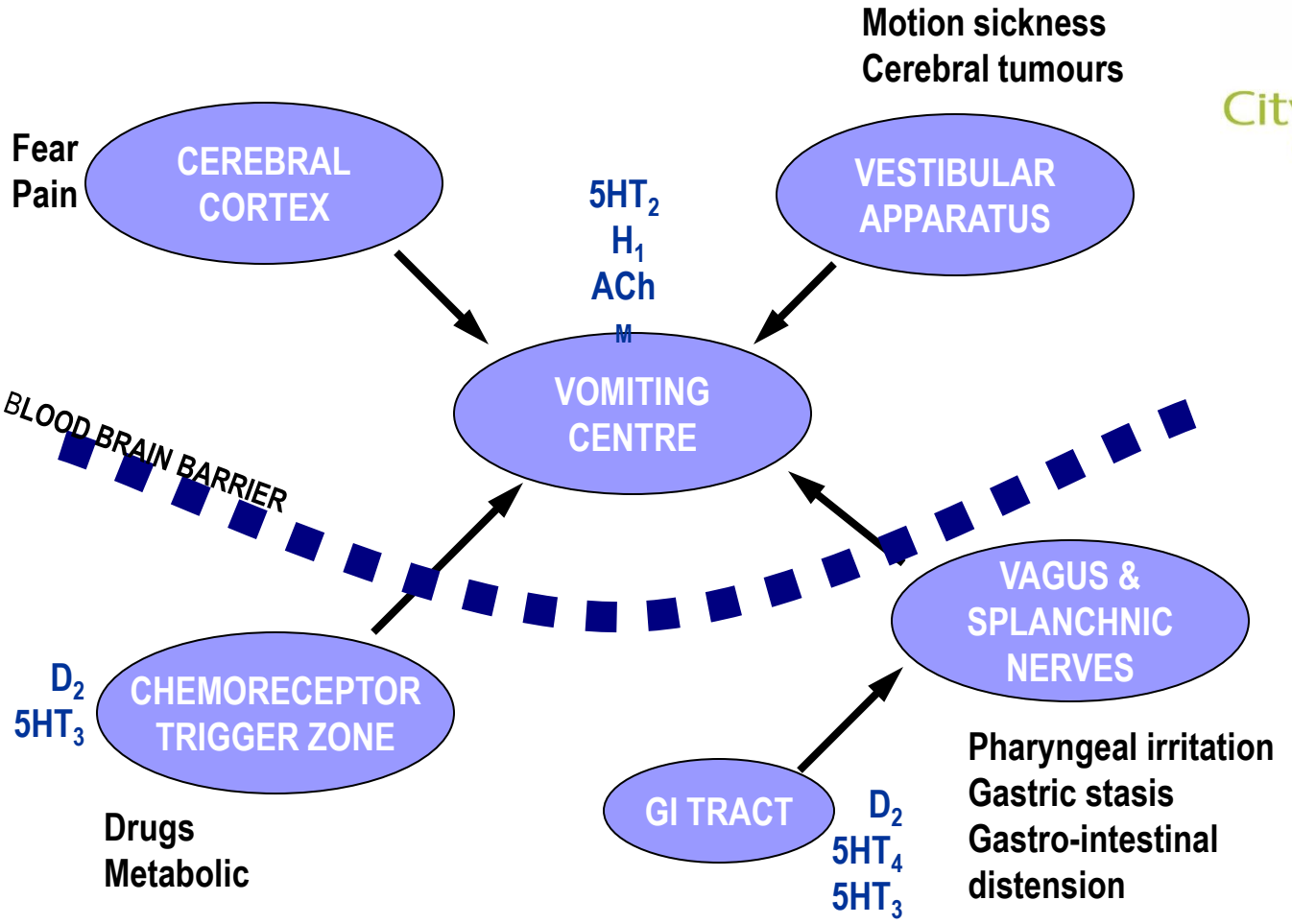
Pathological – think anatomy local, GI, metastases

Chemotherapy

Metabolic

Drug (non-chemotherapy)

Mood, anxiety, fear



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Gastric outflow obstruction -

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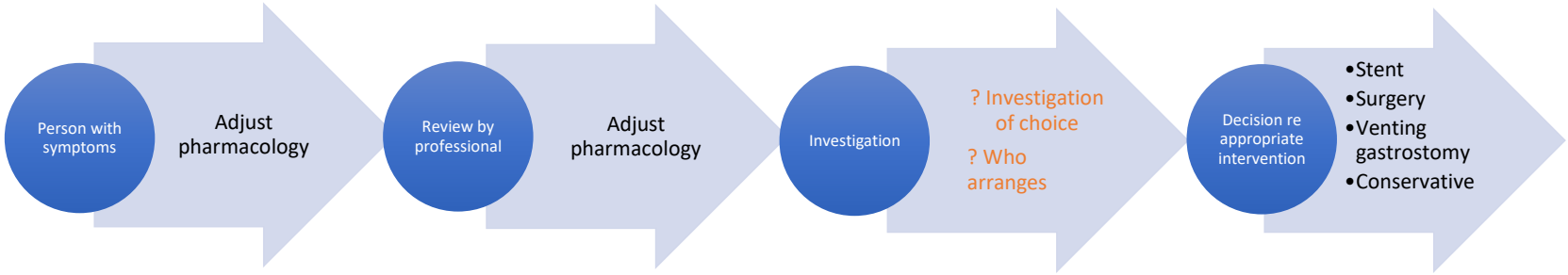
What does the patient report?
Subjective and objective observations



Case study 2

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- 84 person
- Dementia and pancreatic cancer
- Admitted following fall on background general deterioration over last year
- CT scan
- Management plan - best supportive care
- Refer to palliative care

Palliative approach

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- Holistic assessment
- Consider all the points earlier (see case study 1)
- GI function
- Pancreatic function
- Pain management
- Future care planning – when less well
  - speed of change, jaundice, blood tests, scans, EoLC

Advance care planning

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- A process of discussion between the patient & their healthcare providers to clarify their wishes in the context of an anticipated deterioration in their condition with attendant loss of capacity to make decision or communicate wishes

- https://www.mywishes.co.uk

Future care planning

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- Advance care planning
- Advance Directive to Refuse Treatment
- Lasting Power of Attorney

Lasting Power of Attorney (LPA)

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- Allows a person to choose other people to make decisions on their behalf should they ever lack the mental capacity to make decisions themselves.
- There are two types of LPA that are valid in England and Wales:
- **LPA for Health and care decisions** - this allows the attorney(s) to make decisions about treatment, care, medication and place of care.
- **LPA for financial decisions** - this allows the attorney(s) to make decisions about financial affairs e.g. paying bills, dealing with the bank and property
- Need to be registered with the Office of the Public Guardian

Tools for use

- Advance care plan
- Anticipatory prescribing
- DNACPR

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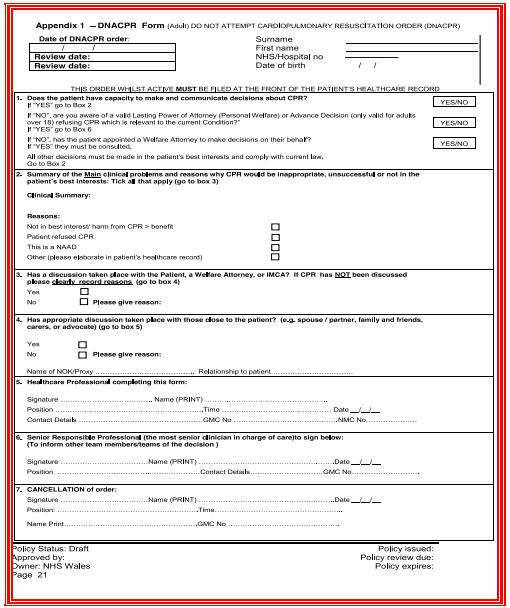


Appendix 1 – DNACPR Form (Adult) DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION ORDER (DNACPR)

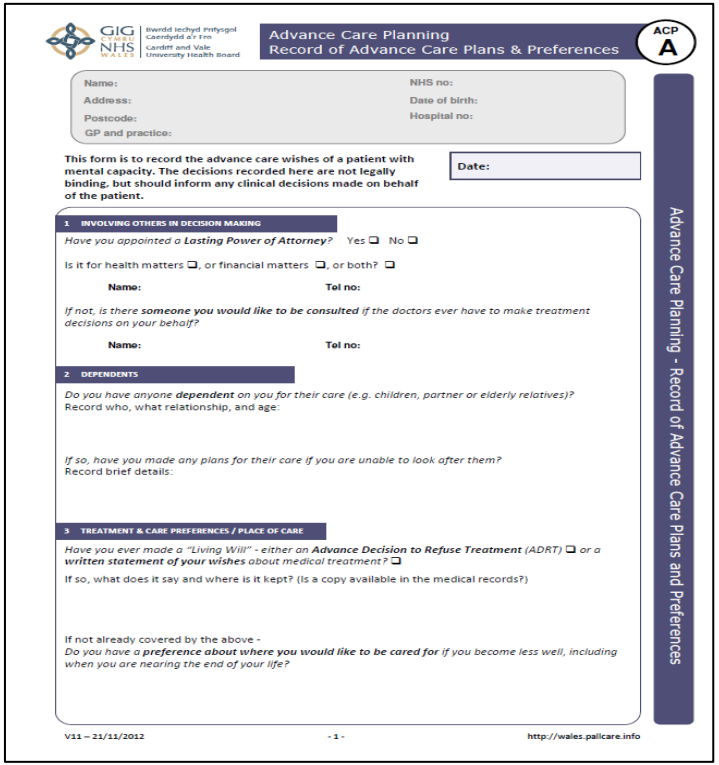
Date of DNACPR order: / /
Review date:
Review date:

Surname
First name
NHS/Hospital no
Date of birth / /

THIS ORDER WHILST ACTIVE **MUST** BE FILED AT THE FRONT OF THE PATIENT'S HEALTHCARE RECORD

1. **Does the patient have capacity to make and communicate decisions about CPR?** YES/NO
   If "YES" go to Box 2
   If "NO", are you aware of a valid Lasting Power of Attorney (Personal Welfare) or Advance Decision (only valid for adults over 18) refusing CPR which is relevant to the current Condition?" YES/NO
   If "YES" go to Box 6
   If "NO", has the patient appointed a Welfare Attorney to make decisions on their behalf? YES/NO
   If "YES" they must be consulted.
   All other decisions must be made in the patient's best interests and comply with current law.
   Go to Box 2
2. **Summary of the Main clinical problems and reasons why CPR would be inappropriate, unsuccessful or not in the patient's best interests: Tick all that apply (go to box 3)**
   Clinical Summary:
   Reasons:
   Not in best interest/ harm from CPR > benefit ☐
   Patient refused CPR ☐
   This is a NAAD ☐
   Other (please elaborate in patient's healthcare record) ☐
3. **Has a discussion taken place with the Patient, a Welfare Attorney, or IMCA? If CPR has NOT been discussed please clearly record reasons. (go to box 4)**
   Yes ☐
   No ☐ **Please give reason:**
4. **Has appropriate discussion taken place with those close to the patient? (e.g. spouse / partner, family and friends, carers, or advocate) (go to box 5)**
   Yes ☐
   No ☐ **Please give reason:**
   Name of NOK/Proxy ..... Relationship to patient .....
5. **Healthcare Professional completing this form:**
   Signature ..... Name (PRINT) .....
   Position .....Time ..... Date __/__/__
   Contact Details .....GMC No .....NMC No.....
6. **Senior Responsible Professional (the most senior clinician in charge of care)to sign below: (To inform other team members/teams of the decision)**
   Signature .....Name (PRINT) .....Date __/__/__
   Position .....Contact Details.....GMC No.....
7. **CANCELLATION of order:**
   Signature .....Name (PRINT) .....Date __/__/__
   Position: .....Time.....
   Name Print.....GMC No .....

Policy Status: Draft
Approved by:
Owner: NHS Wales
Page 21
Policy issued:
Policy review due:
Policy expires:



GIG CYMRU NHS WALES — Bwrdd Iechyd Prifysgol Caerdydd a'r Fro / Cardiff and Vale University Health Board

Advance Care Planning
Record of Advance Care Plans & Preferences

ACP A

Name:
Address:
Postcode:
GP and practice:
NHS no:
Date of birth:
Hospital no:

This form is to record the advance care wishes of a patient with mental capacity. The decisions recorded here are not legally binding, but should inform any clinical decisions made on behalf of the patient.

Date:

1 INVOLVING OTHERS IN DECISION MAKING

Have you appointed a ***Lasting Power of Attorney****?* Yes ❑ No ❑

Is it for health matters ❑, or financial matters ❑, or both? ❑

Name: **Tel no:**

If not, is there ***someone you would like to be consulted*** *if the doctors ever have to make treatment decisions on your behalf?*

Name: **Tel no:**

2 DEPENDENTS

Do you have anyone ***dependent*** *on you for their care (e.g. children, partner or elderly relatives)?*
Record who, what relationship, and age:

If so, have you made any plans for their care if you are unable to look after them?
Record brief details:

3 TREATMENT & CARE PREFERENCES / PLACE OF CARE

Have you ever made a "Living Will" - either an ***Advance Decision to Refuse Treatment*** *(ADRT) ❑ or a* ***written statement of your wishes*** *about medical treatment?* ❑

If so, what does it say and where is it kept? (Is a copy available in the medical records?)

If not already covered by the above -
Do you have a ***preference about where you would like to be cared for*** *if you become less well, including when you are nearing the end of your life?*

Advance Care Planning - Record of Advance Care Plans and Preferences

V11 – 21/11/2012 - 1 - http://wales.pallcare.info

Case study 3

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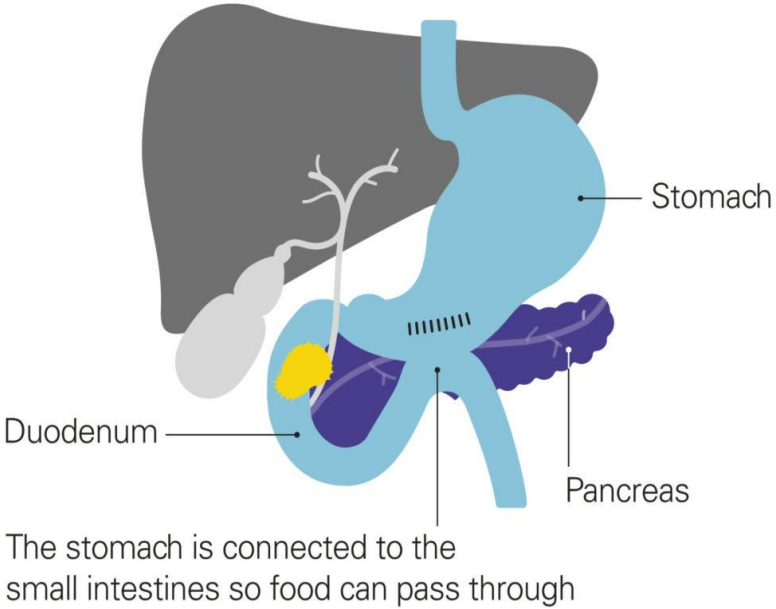
- 74-year-old retired, lives alone
- Palliative bypass surgery
- Chemotherapy – 3 different lines – ongoing treatment
- Rising tumour markers
- More frail
- Telephone palliative care reporting unwell and more breathless



Signs/Symptoms suggestive of deterioration in health

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- Rising tumour markers
- CT scans show progressive disease
- Deteriorating performance status
- Fatigue
- Weight loss/cachexia
- Breathlessness
- Reduced oral intake - food, fluids
- Difficulty swallowing medication

Is there something reversible here?

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Does she want it investigated or fixed ?

Thromboembolic disease – consider with progressive or sudden breathlessness

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- Incidence of thromboembolism with adenocarcinoma of pancreas is 7x higher

Situations where people are anticoagulated:

- Prophylaxis whilst inpatient
- Prophylaxis considered when receiving chemotherapy (NICE)
- Treatment if DVT/PE identified

Management of general deterioration

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- Identify the cause(s)
- Investigate and treat reversible causes appropriately
- Has the patient made any advance care plan which has a bearing on the situation?
- Consider is this an End-Of-Life event?
- Treat symptoms
  - Non- drug treatment – maximise independence, consider goals, revisit equipment and care needs
  - Family support
  - Drug treatment/rationalise medications

Case study 4

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- 65-year-old man, mowing lawn, recently completed chemotherapy
- CT scan
- Painless jaundice
- Appropriate intervention?

Biliary obstruction and stents

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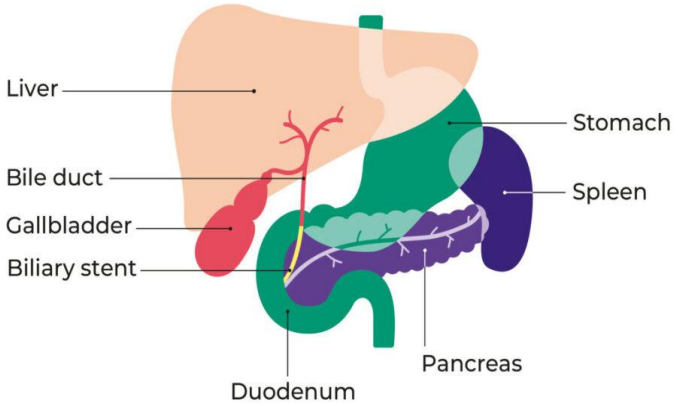
Jaundice – biliary obstruction or liver failure?

Investigation – blood tests, scan

Location, Location!!



Stent related complications:

- Infection
- Occlusion from tumor growth/sludge
- Migration
- Differentiating liver failure from occlusion of bile duct or stent

Case study 5

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- 65-year-old lady
- Obstructive jaundice, stented
- Chemotherapy – 3 lines,
- Principle physical symptoms, pain, altered bowel habit, nausea and vomiting and increasing abdominal distension

Ascites

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Summary of interventions to relieve GI symptoms

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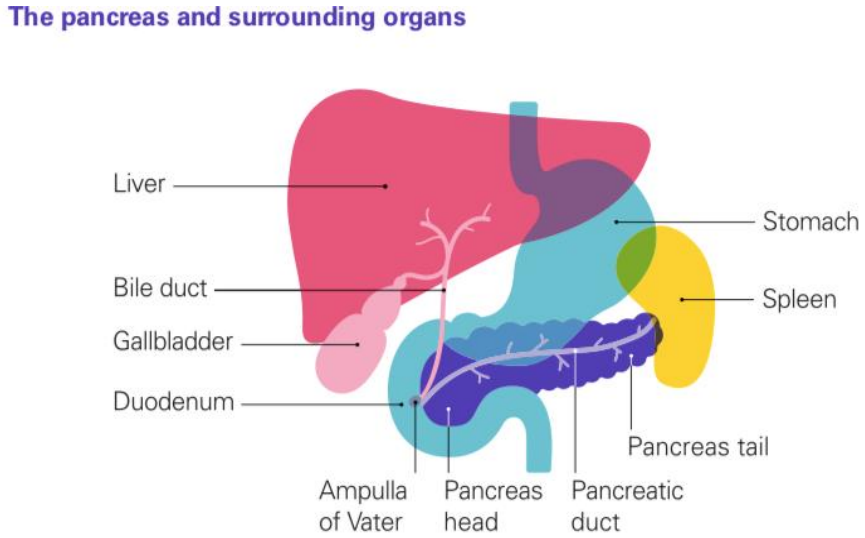
Possible interventions to consider – relevance of timing

- Gastric outflow obstruction
- Biliary obstruction
- Ascites



End of life care

Consider the cancer illness in context

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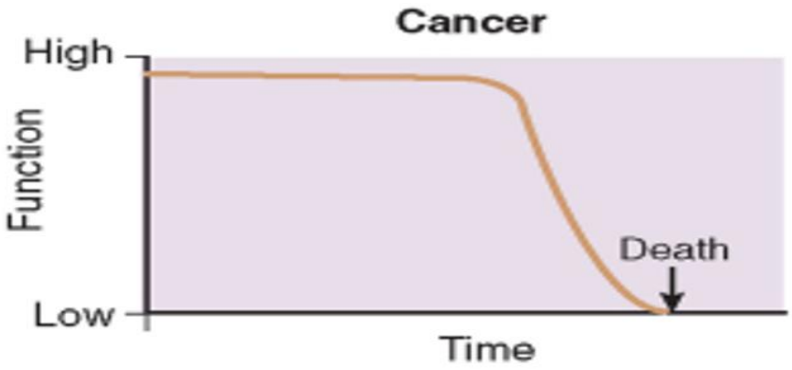
- Place current situation into longer context



Preparation for End-of-Life care

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- Communication – patient
- Medication – rationalise and plan ahead, based on symptom experienced & those anticipated
- Plan for blood sugars management
- Oral intake +/- PERT
- Equipment
- Pressure relief
- Ablutions & continence - dignity
- Communication with the family (expectations, how to support, fears & concerns)
- Reiterate contact details for health professionals (palliative care, District nursing, GP OOH)
- What to do after death
- Communication with other health professionals

Communication – difficult conversations

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Cardiff 6-point tool kit

- Comfort
- Language
- Listening & Silence
- Question style
- Reflection
- Summary

Specific symptoms at EOL: pain

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- Common – SUPPORT study 40% ‘had severe pain most of the time’ in the last 3 days of life
- Investigate only if it will change management in the context of the individuals ACP & circumstances
- Consider alternative routes for medication
- Empower family members
- If on transdermal patches – ***continue patch*** and add subcutaneous medication to this as required

Anticipatory medication

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- Route
- Drug Availability
- Pain/breathlessness – morphine/oxycodone
- Vomiting – metoclopramide/levomepromazine
- Agitation – midazolam
- Respiratory secretions – glycopyrronium/hyoscine hydrobromide
- Water for injection
- Mouth care

Subcutaneous route

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- Safe and reliable route to use for patients who are dying
- Can deliver regular medication or ‘just in case’ PRN medication
- Every patient should have provision for ‘just in case’ PRN medication

but

Not every dying patient needs a syringe driver

Summary

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- Communication – person, those closest to them & multiprofessional
- Planning - progressive & evolving situation
- Essential for ongoing reassessment
- Support – based on patient & families' preferences
- Safety netting

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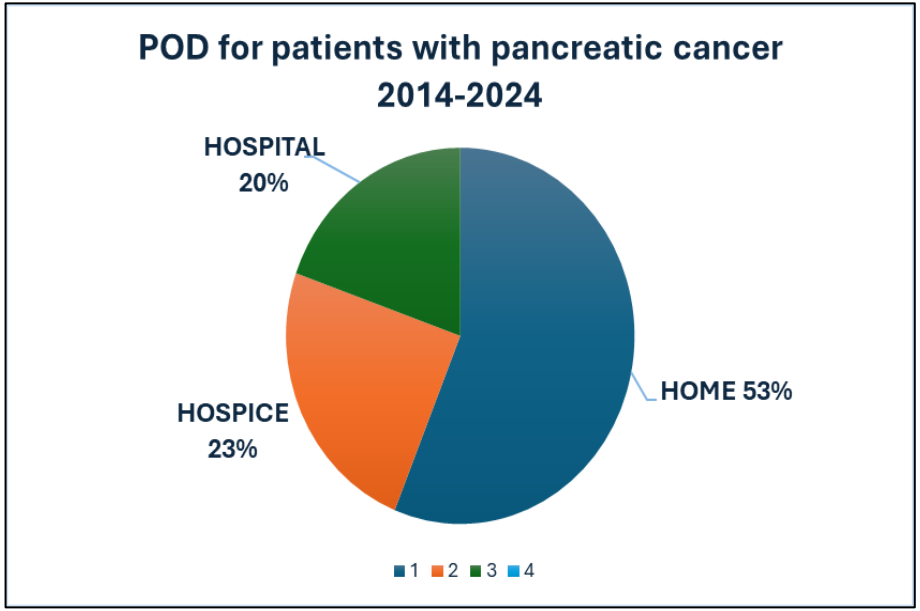

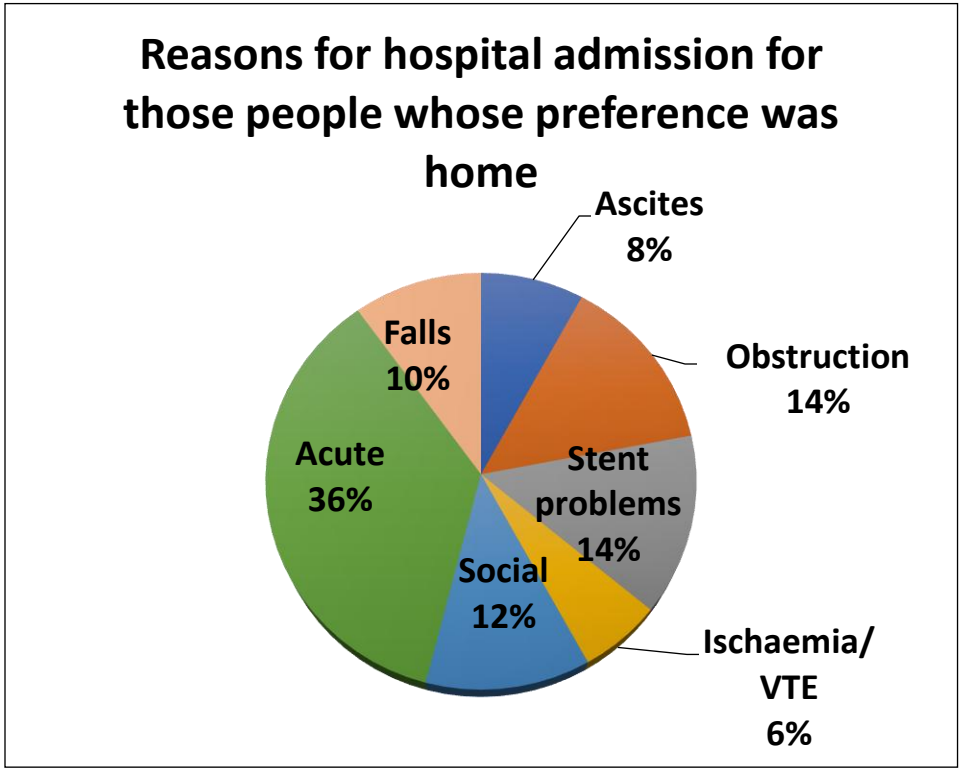

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Supplementary slides for specific questions

Diabetes management

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- 1 in 100 with new onset diabetes are diagnosed with pancreatic cancer within 3 years
- 25% of people diagnosed with pancreatic cancer were originally diagnosed with diabetes
- Type 3c diabetes or ‘pancreatogenic’ diabetes caused by damage to pancreas related to tumour
- All patients with pancreatic cancer will need regular monitoring of BMs

Diabetes & EOLC

Type 3c not specifically covered by this guidance.

When planning for EoLC – consider the medications that have been used to manage diabetes prior to deterioration.

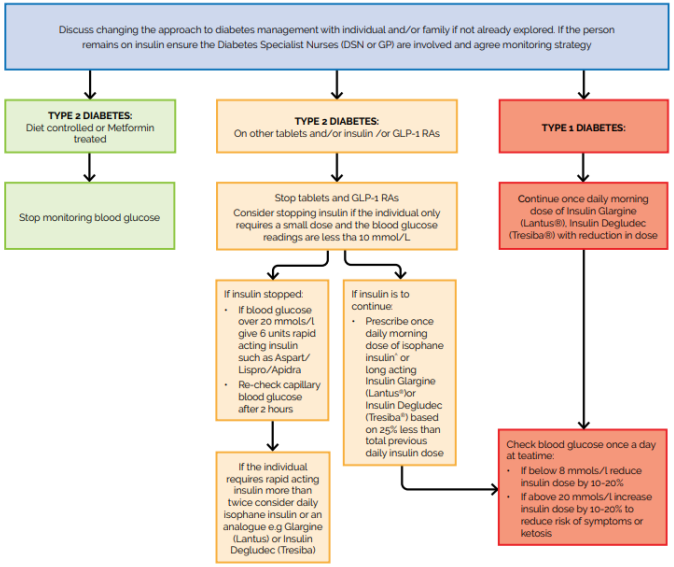
Care Decisions for the Last Days of Life

gofal lliniarol CYMRU – WALES palliative care

All Wales Supplementary Symptom Control Guidance for palliative management of patients with diabetes

The algorithm for the last days of life shown below is copied directly from page 21 of the 'End Of Life Guidance For Diabetes Care' for healthcare professionals document. (Trend Diabetes, November 2021, available online: https://diabetes-resources-production.s3.eu-west-1.amazonaws.com/resources-s3/public/2021-11/EoL_TREND_FINAL2_0.pdf)

Figure 1 - Algorithm for the last days of life



IMPORTANT INFORMATION:

- Aim for capillary blood glucose readings of 6-15 mmol/L
- Keep tests to a minimum. It may be necessary to perform some tests to ensure unpleasant symptoms do not occur due to low or high blood glucose
- It is difficult to identify symptoms due to "hypo" or hyperglycaemia in a dying person
- If symptoms are observed it could be due to abnormal blood glucose levels
- Test urine or blood for glucose if the person is symptomatic
- Observe for symptoms in previously insulin treated individual where insulin has been discontinued.
- Flash glucose monitoring may be useful in these individuals to avoid finger prick testing

Diabetes Management Supplement – Care Decisions Guidance v12 May 2023. Review June 2025.

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Advance decision to refuse treatment (ADRT)

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- Legally binding
- An advance decision to refuse specific medical treatment
- Specify the medical circumstances
- May include resuscitation
- Effective when individual looses capacity to make decisions about treatment

(including giving or refusing consent to treatment)

ADRTs for ‘life sustaining treatment’

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To be legally binding ADRTs of life sustaining treatment must be:-

- Written, signed by patient AND independent witness
- specify circumstances in which it should apply
- include the statement “even if my life is at risk as a result”
- involves assessment of capacity when made
- professional needs to consider validity before acting on it
- an ADRT cannot override comfort measures like warmth, shelter and basic care (hygiene and offers of food and water by mouth).