NHS
Greater Glasgow and Clyde

Palliative Care
It's Everyone's Business

Allison O'Donnell
Practice Development Nurse
Specialist Learning Disability Services
Greater Glasgow and Clyde

PCPLD Network
Palliative Care for People with Learning Disabilities

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Palliative Care for People with Learning Disabilities

We aim to raise awareness of the palliative care needs of people with learning disabilities, to share and promote ‘best practice’ and to enhance collaboration between all services providers, carers and people with a learning disability.

A SHOWCASE FOR EXCELLENCE IN PALLIATIVE CARE PROVISION FOR PEOPLE WITH LEARNING DISABILITIES

PCPLD NETWORK 20TH ANNIVERSARY CONFERENCE

Keynote Speakers

Prof Bee Wee and Dr Jean O'Hara
NHS England National Clinical Directors for Palliative Care and for Learning Disability

Linda McEnhill and Dr Noëlle Blackman
Founders of the PCPLD Network

Dr Irene Tuffrey-Wijne
Associate Professor in Palliative Care and Intellectual Disability

Other Speakers Include

Allison O'Donnell Specialist Learning Disability Services, Greater Glasgow & Clyde
Melanie Davies Morriston Hospital, Swansea; Winner of RCN Nurse of the Year 2017
Dr Corinne Midgley Saint Francis Hospice, Romford
Louise Ellis Foster Carer, Winner of 2016 Linda McEnhill Award
GRASSroots group of people with learning disabilities, London
Performance by people with learning disabilities from the **Baked Bean Theatre Company**

COST: £100 early bird (payment received before 31 March 2018) and £150 thereafter
Lunch and refreshments included.

WHO IS IT FOR?: This conference will be of interest to anyone who is involved in supporting people with learning disabilities who are reaching the end of life, and those who are bereaved. That includes families, carers, health and social care staff, service providers and commissioners. All delegates will receive a certificate of attendance.

POSTERS: Abstracts are invited on any topic relevant to palliative care for people with learning disabilities. For details, see booking form.

Wednesday13th June 2018, 09.30-16.30
Friends House, 173 Euston Road, London NW1 2BJ

TO REGISTER for the conference, go to www.pcpld.org

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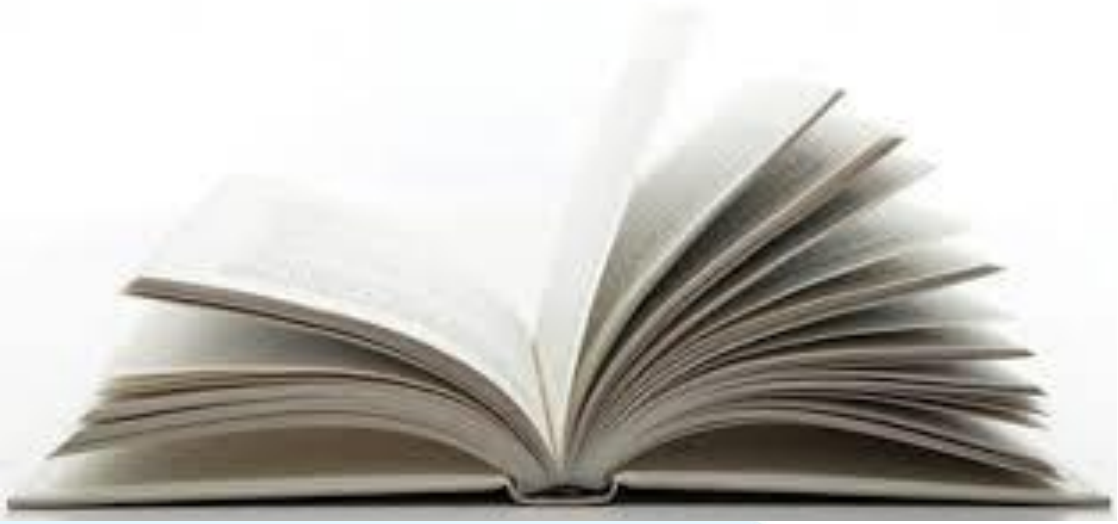

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Consideration's : Learning Disability and Palliative Care

- Diagnosing ill health is difficult
- Increasing population
- Poorer health and more complex health issues. Different disease profiles
- High incidence of premature deaths in LD population
- Health Inequalities and Discrimination

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Diagnosis

- Recognising ill health
- Communication
- Screening
- Diagnostic overshadowing
- Attitudes and assumptions
- Institutional Discrimination
- Accessing services

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Increasing Population

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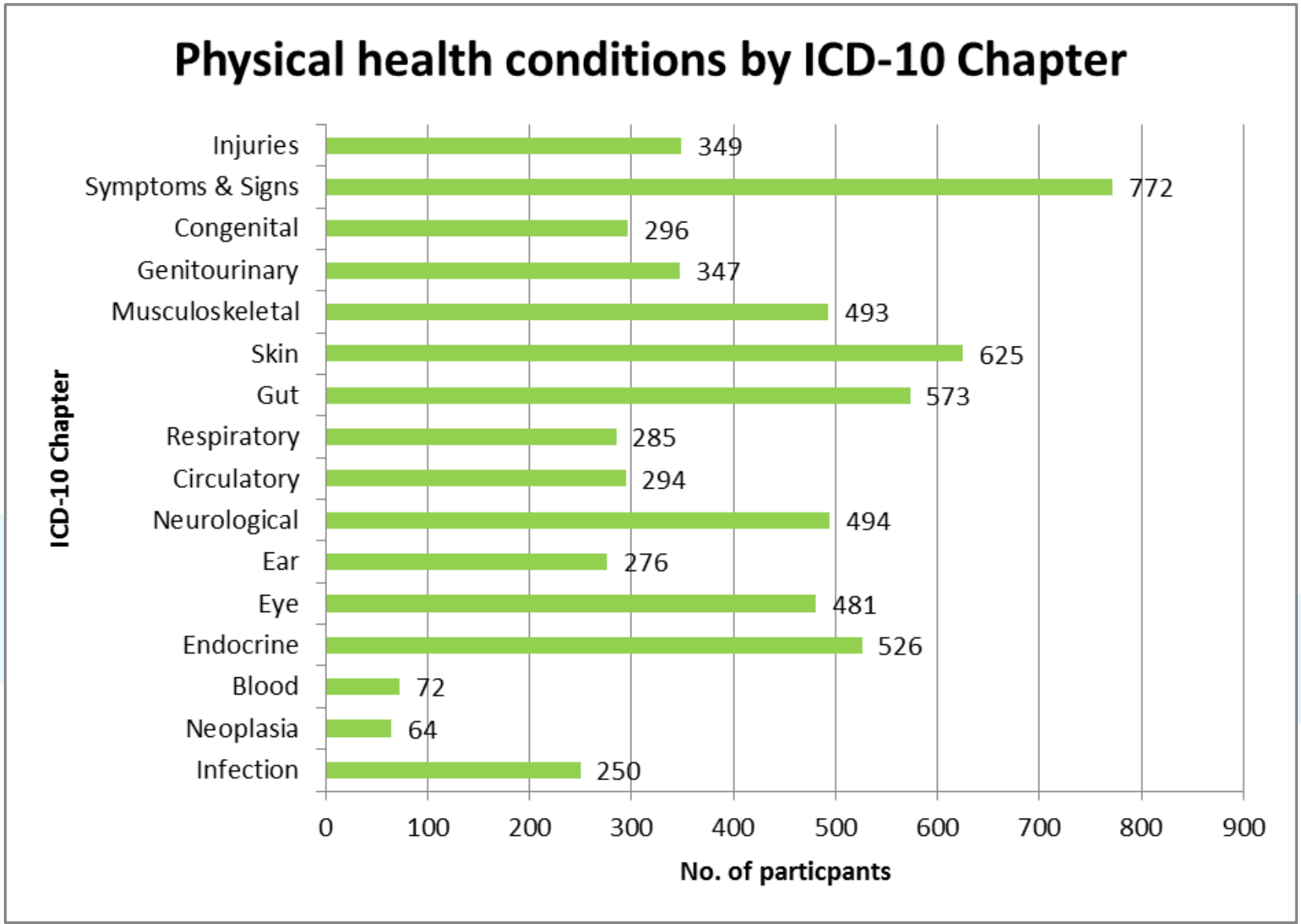
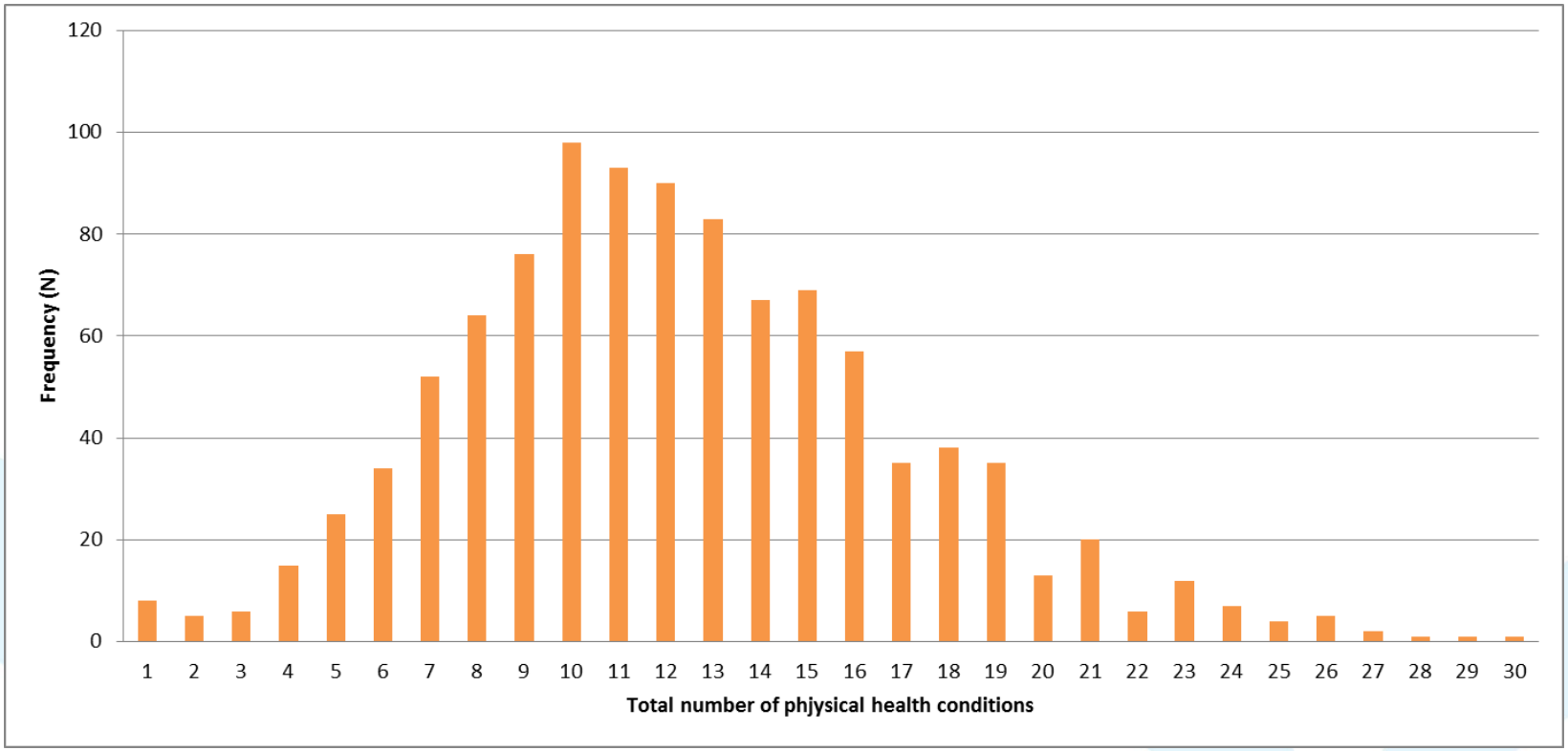
What are the most prevalent physical health conditions?



What is the extent of multi-morbidity for this cohort?



Different Disease Profiles

- Respiratory Disease
- Coronary Heart Disease
- Gastrointestinal Cancer
- Dementia

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Premature Deaths

- Lower life expectancy

  The average life expectancy for **women** with learning disabilities is 20 years lower (compared to the general population)

  The average life expectancy for **men** with learning disabilities is 13 years lower (compared to the general population)

- Increased risk of premature death

  22% of people with learning disability were under the age of 50 when they died

  42% of deaths were considered premature.

CIPOLD 2013

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Health inequalities and Discrimination

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- Poor access to health services
- Inadequate health service responses
- Other causes or determinants of health inequalities such as poverty, housing, employment, social isolation and discrimination and the lifestyle 'choices'

- Less likely to receive opioid analgesia in their final illness
- Less likely to have access to specialist palliative care
- There deaths were sometimes described as not being planned for, uncoordinated and poorly managed. (CIPOLD 2013)

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Consideration's: Palliative Care and Learning Disability

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

World Health Organisation 2010

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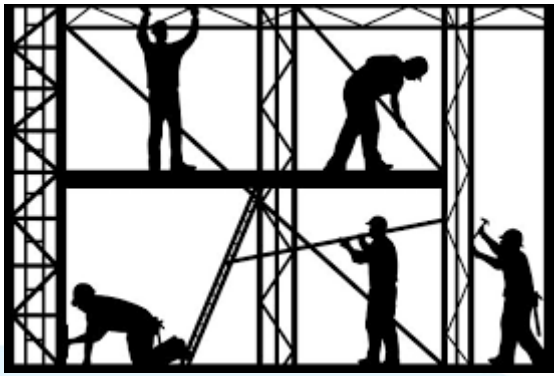
The palliative care framework



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The palliative care framework supports people irrespective of stage of disease or condition :

- early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy,
- living with complex health needs and co morbid conditions
- living with chronic disease
- approaching end of life care and
- support for those who grieve

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End of Life Care

People who 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 hours or days) and those with:

- Advanced progressive incurable conditions
- Generally frail and co existing conditions that mean they are expected to die within 12 month
- 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

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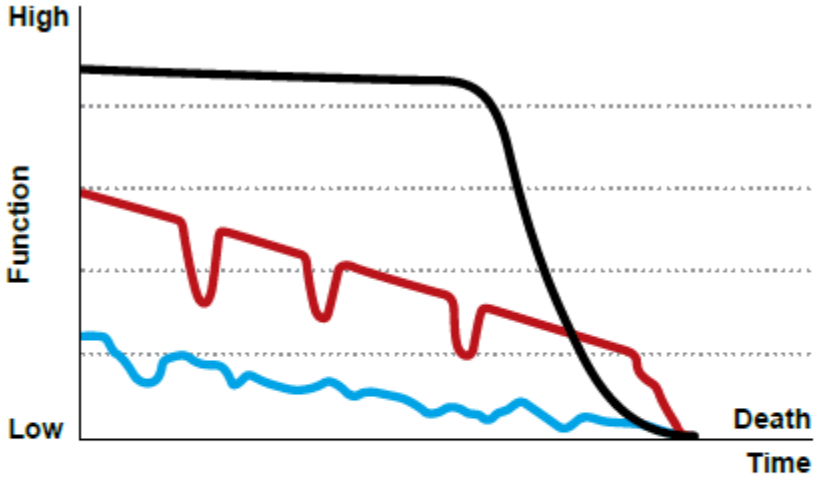
Trajectory in palliative care



Source: Murray, S.A. et al[1]

- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)

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- Deaths due to underlying causes which are likely to benefit from some degree of palliative and end of life care
- A substantial shift in place of death from hospital to communities
- Prognostic Indicators
- Lives lived in communities

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Gold Standard Framework

Identify- GSF Prognostic Indicator Guidance-

identifying pts with advanced disease in need of palliative/ supportive care/for register

Three triggers:

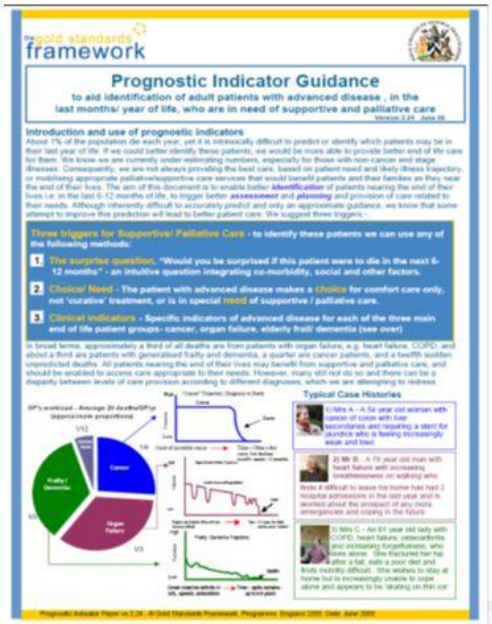
1. **Surprise question-**

'Would you be surprised if this person was to die within the next year?'

2. **Patient preference** for comfort care/need

3. **Clinical indicators**

Suggested that all pts on register are offered an ACP discussion


the gold standards framework

Prognostic Indicator Guidance

to aid identification of adult patients with advanced disease , in the last months/ year of life, who are in need of supportive and palliative care

Introduction and use of prognostic indicators

Three triggers for Supportive/ Palliative Care - to identify these patients we can use any of the following methods:

1. The surprise question, "Would you be surprised if this patient were to die in the next 6-12 months" - an intuitive question integrating co-morbidity, social and other factors.
2. Choice/ Need - The patient with advanced disease makes a choice for comfort care only, not 'curative' treatment, or is in special need of supportive / palliative care.
3. Clinical indicators - Specific indicators of advanced disease for each of the three main end of life patient groups- cancer, organ failure, elderly frail/ dementia (see over)

Typical Case Histories

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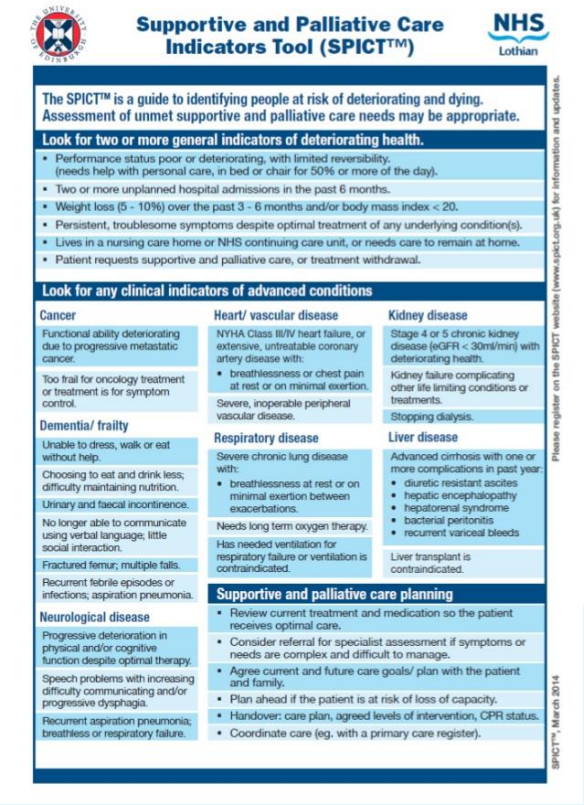

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of deteriorating and dying. Assessment of unmet supportive and palliative care needs may be appropriate.

Look for two or more general indicators of deteriorating health.

- Performance status poor or deteriorating, with limited reversibility. (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

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

Dementia/ frailty

Unable to dress, walk or eat without help.

Choosing to eat and drink less; difficulty maintaining nutrition.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

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

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

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

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

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

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

Liver transplant is contraindicated.

Supportive and palliative care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg. with a primary care register).

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, March 2014

SPICT

Supportive and Palliative Care Indicators Tool.

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- Anticipatory care planning
- Difficult conversations
- Support the individual to gain an understanding of condition and prognosis
- Decision making and Choice
- Dignity and Value
- Joint Assessment -Person centred, holistic assessment of physical, social, emotional and spiritual aspects of care
- Coordination of care and health advocacy
- Partnership and collaborative working to improve patients outcomes
- Better outcomes for the individual and those who care for them

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- Identify the knowledge and skills required by health and social care staff.
- Education
- Partnership and Collaborative Working

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Supporting people with learning disabilities through the palliative care journey

NHS Greater Glasgow and Clyde Learning Disabilities and Palliative Care Pathway

The Scottish Government

The Prince & Princess of Wales Hospice

NHS Greater Glasgow and Clyde

Identification Of Concern

Known Palliative Care (PC) needs. Symptoms. Decline using Prognostic Indicators. Screening

Recognise Triggers

Referral to GP for Clinical Assessment

Admission to Acute Setting

Plan

Comprehensive Investigations

Referral to Learning Disabilities (LD) Nurse through Community Learning Disabilities Team (CLDT)

Support with Health Needs. Discharge as appropriate when outcomes are met

Identified Palliative Care Needs. In addition consider support required if relative or carer has a Learning Disability.

Consider use of rapid discharge algorithm within acute care if appropriate

Referral to LD Nurse if not already done

Assessment, Care Planning, Review and Co-ordination

Holistic assessment of needs, including DisDAT and consider use of the Health Equalities Framework (HEF) www.disdat.co.uk

Holistic and Person Centred Care coordinated by Learning Disabilities Nurse or appropriate other in partnership and collaboration with generalist and specialist services, family and carers

Ensure availability of accessible information for patient/family/carers. Consider Training Needs as appropriate

Identify/Establish Clinical and Social Care Team including appropriate primary generalist and specialist services refer to Considerations For Care

Is patient aware of diagnosis?
Yes - Consider support needs and discuss wishes
No - Consider:
What- Information to be given
Where - the various locations involved
When - the process will start
Who - will be involved in this process

Review, including the "Surprise Question" and Gold Standards Framework if appropriate
www.goldstandardframework.org.uk

Review patients wishes

Communicate Plans to All

Support patient to live with condition and plan for sudden deterioration

Review clinical team

If appropriate discuss and identify patient wishes:
Preferred priorities for care including Advance Care Plan, Anticipatory Care Plan, What's Important now, place of care, Life Story Work, Organ Donation, Legal Will, Do Not Attempt Cardiopulmonary Resuscitation (DNACPR), Funeral Planning

Refer to Considerations for Care to support patient living with condition and aid Care Planning

Review and Adapt Care Plan as appropriate

Recognise signs of decline / Identify if patient is at risk of sudden decline using Supportive and Palliative Care Indicator Tools (SPICT), GoldStandards Framework (GSF) or other Prognostic tools - Include "Surprise Question" www.spict.org.uk

Plan for crisis/sudden deterioration / crisis considering also the priorities in the last weeks of life:
Symptom Management
Oncological Emergencies
Environmental Issues
Resource
Other Professional Involvement
Scottish Palliative Care Guidelines
www.palliativecareguidelines.scot.nhs.uk/

Review patients wishes

Communicate Plans to All

Care in the last weeks of life (Time is short)

Review clinical team

In partnership with Primary Care Team or Palliative Care Team as appropriate:

- Out of Hours support is established including contact details
- Anticipatory prescribing is considered - Just in case box
- Verification of expected death documentation considered
- DNACPR considered and discussed with all
- Gold Standard Framework Review
- Palliative Care Electronic Register
- Consider current needs in relation to aids and equipment
- DNACPR
- Thinking Ahead and Making Plans

Ensure additional support needs are established and resourced to maintain preferred place of care

Patient / Family / Carer/ Peer Support considered as Philosophy of Care changes

Review adapt care plan as appropriate

Review patients wishes

Communicate Plans to All

Care in the last days of life

Review clinical team

Consider "Guidance for Person-Centred Care in the last Stages of Life" Greater Glasgow and Clyde (GG&C) to support holistic care
Also referred to "Guidance at end of Life" GAEL
Guidance for End of Life Care

Advance Care Plan

Patient / Family / Carer / Peer Support considered as philosophy of care changes

Review adapt care plan as appropriate

Review patients wishes

Communicate Plans to All

Care after death

When someone dies at home

- Contact GP's surgery during Surgery Hours **OR**
- Contact District Nurse if Verification of Expected Death documentation (VOED) in place **OR**
- Contact NHS 24 (Tel: 111) if no VOED in place

Contact Nearest Relative if not already done

Contact relevant Spiritual Support if appropriate

Contact GP or NHS 24 outwith surgery hours if Organ Donation is being considered

Contact Funeral Director to remove deceased from home

Collect Death Certificate from GP surgery (or hospital if patient has died in hospital)

Register the death within 8 days at the Register of Births, Marriages and Deaths Office

Contact Funeral Director to arrange funeral

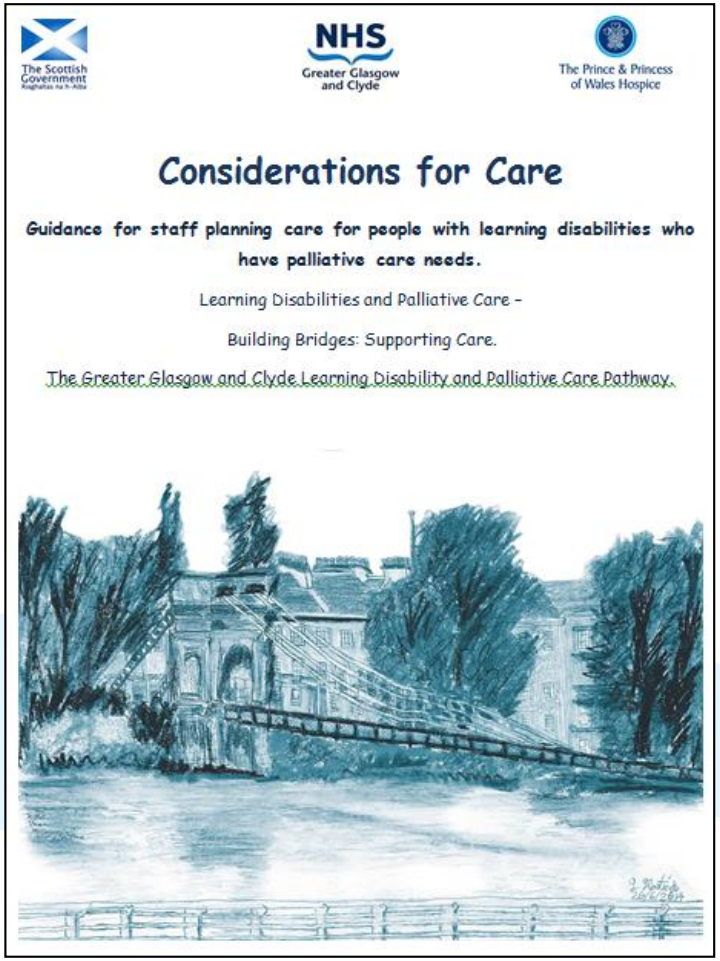
Bereavement Support

Family / Carer / Peer Support Sensitive practical support such as uplift of equipment

All underpinned by:

Legal framework | **Communication** | **Collaboration** | **Co-ordination**

A skilled, knowledgeable and confident workforce :



The Scottish Government

NHS Greater Glasgow and Clyde

The Prince & Princess of Wales Hospice

Considerations for Care

Guidance for staff planning care for people with learning disabilities who have palliative care needs.

Learning Disabilities and Palliative Care –

Building Bridges: Supporting Care.

The Greater Glasgow and Clyde Learning Disability and Palliative Care Pathway.

Are you in ?

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Allison.O'Donnell@ggc.scot.nhs.uk

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