Supporting people with learning disabilities through the palliative care journey

**NHS Greater Glasgow and Clyde Learning Disabilities and Palliative Care Pathway**

**Identification Of Concern**
- Recognise Triggers
- Referral to GP for Clinical Assessment
- Admit to Acute Setting

**Assessment, Care Planning, Review and Co-ordination**
- 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.
- Support with Health Needs. Discharge as appropriate when outcomes are met.

**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
- Review and Adapt Care Plan 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 (GSF) or other Prognostic tools - include “Surprise Question”
- 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
- Review adapt care plan as appropriate
- 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
- 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
- Review and Adapt Care Plan as appropriate
- Ensure additional support needs are established and resourced to maintain preferred place of care
- Advise Care Plan, What's important now, place of care, Life Story Work, Organ Donation, Legal Will, Do Not Attempt Cardiopulmonary Resuscitation (DNACPR), Funeral Planning
- 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
- Register the death within 8 days at the office
- Contact GP’s surgery during Surgery Hours OR
- Contact Nearest Relative if not already done
- Request DVLA to change registration
- Register the death within 5 days at the office

**Legal framework**
- Equalities Framework (HEF)
- DisDAT and consider use of the Health Framework (GSF) or other Prognostic Indicator Tools (SPICT), Gold Standards Framework
- Review clinical team
- Consider current needs in relation to aids and equipment

**Communication**
- All underpinned by:
- Peer Support considered as Philosophy of care changes
- Patient / Family / Carer / Peer Support considered as philosophy of care changes
- Review patients wishes
- Communicate Plans to All

**Collaboration**
- Review patients wishes
- Communicate Plans to All

**Co-ordination**
- Review patients wishes
- Communicate Plans to All

**Referral to LD Nurse if not already done**
- Consider use of rapid discharge algorithm within acute care if appropriate
- Identify 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