End of Life Care Checklist

The aim of this checklist is to enable Learning Disability Nurses to have an increased knowledge and awareness when supporting a person with a learning disability and their carers during the final stages of their life. Early identification enables us to work with other services, for example, specialist palliative care nurses and hospices to provide an effective and holistic approach to end of life care.

This checklist has been produced in collaboration with the Community Palliative Team at Rowcroft Hospice and Teignbridge/South West Devon Learning Disability Community Teams for people in the last 6-12 months of life. This could include people with: cancer, dementia and other life-limiting illnesses.

It is recommended that this is used alongside national and local End of Life Policies.

PERSON DETAILS	
Name	
Address	
Date of Birth	
Contact Telephone No.	
G.P.	
Next of Kin	
Diagnosis	

Contact details for Professionals involved	
Name	**Address/Telephone number**

PHYSICAL

		DATE	DATE	DATE
Capacity		/ /	/ /	/ /
Mental Capacity Assessment				
Best Interest meeting				
Date:	**ACTION:**			
Communication				
Baseline communication – has this changed?				
Has a prognosis of terminally ill/dying been confirmed?				
Does the person know?				
If not, consider who should tell them, when and how				
Consider different/best methods, e.g. Dictaphone, photos, video				
Consider sensory methods, e.g. visual, touch, etc				
Relevant photos of visits e.g. hospital				
Does the person need a Talking Mat?				
Would the person like counselling to help them come to terms with their illness?				
Date:	**ACTION:**			
Pain				
Assess their pain				
Has a DISDAT assessment been completed?				
Is medication prescribed - Regular & PRN				
Is there a pain care plan?				
Are there individualised pain charts?				
Re-assess and Review				
Date:	**ACTION:**			

		DATE	DATE	DATE
Medication		/ /	/ /	/ /
Consider prescription medication –prioritise in order of necessity				
Form of medication (tablet, syrup, syringe driver)				
Is person experiencing any side effects?				
Chemo and radiotherapy – easy read information				
Anticipatory prescribing – held within Home in case of pain, nausea, etc. contact District Nurse/GP				
Is Emergency Medicine held at local hospital, GP, or Chemist for access during Out of Hours?				
Should medication care plans be in place? e.g. when & how				
Compliance and concordance				
Date:	**ACTION:**			
Mobility				
Baseline mobility – has this changed?				
Physio/exercises, correct & regular change of positioning				
Risk assessments – moving & manual handling				
Pressure relieving aids (District Nurses) – equipment, hoists, mobility aids (sticks)				
Maintain mobility & movement				
Date:	**ACTION:**			
Breathlessness				
Is the person breathless?				
Causes – e.g. anxiety, progression of disease				
Exercises – would a referral to Physio be beneficial?				
How to manage your life - planning, pacing & prioritising your day –consider referral to OT				
Courses available for patients				
Medication and oxygen				
Symptom control diary				
Date:	**ACTION:**			

		DATE	DATE	DATE
Fatigue		/ /	/ /	/ /
Is OT involvement necessary?				
Is the person feeling tired/fatigued?				
Consider energy conservation, e.g. pacing the day's activities				
Task management				
Consider use of medication (steroid)				
Date:	**ACTION:**			
Nausea & Vomiting				
Is the person feeling nauseous/any signs of vomiting?				
Are they showing signs of dehydration?				
Have they lost their appetite?				
Consider positioning				
Is the person having sensory changes? i.e. foods smelling or tasting unpleasant				
Is it treatment related? – radio/chemotherapy, medication				
Has an anti-emetic medication been considered?				
Is oral hygiene being maintained?				
Has oral thrush been assessed?				
Are they showing signs of anxiety – gripes/butterflies				
Are there any physical signs – light headedness, weakness				
Have specific care plans/risk assessments been written?				
Date:	**ACTION:**			
Eating & Drinking				
Is there a change? Refer to SaLT, Dietician, OT, GP ?				
Hydration/Supplementary foods - PEG/IV, e.g. Ensure/Fortisip				
Weight – Nutritional risk (Malnutrition Universal Screening Tool)				
Care plans & risk assessments				
Equipment – refer to OT				
Personalised Eating Plan				
Presentation of food				
Maximising nutritional value – useful tips e.g. food supplementing, kiwi, pineapple				
Date:	**ACTION:**			

		DATE	DATE	DATE
Sleep		/ /	/ /	/ /
Has sleep pattern changed? (Pattern Reversal)				
Is pain, fear or anxiety preventing sleep?				
Is equipment needed to help with correct positioning, e.g. bed, extra pillows, air mattress				
Is environment appropriate for sleep, e.g. noise levels, lighting, temperature of room				
Would relaxation help e.g. aromatherapy, soft music, massage				
Is medication required?				
Date:	**ACTION:**			
Skin Integrity				
Assess skin integrity – Waterlow Score				
Causes: lack of movement, shearing				
Regular observations (care plan & recordings)				
Prevention:				
- Referral to Tissue Viability Nurse,				
- Equipment – air mattress/cushions,				
- Moving & manual handling				
- Nutrition & loose clothing				
Medication – creams, lotions, pain relief				
Lymphoedema – refer to specialist				
Date:	**ACTION:**			
Continence				
Assessment – has there been any change?				
Access to toilet/commode				
Refer to continence advisor (equipment, pads)				
Care planning & risk assessment				
Monitoring – bowels, urine, catheterisation, UTI				
Medication				
Date:	**ACTION:**			

		DATE	DATE	DATE
Knowing when to refer and to whom		/ /	/ /	/ /
Community Learning Disability Team				
Consultants and GP				
Dietician				
District Nurses				
Holistic/Complimentary Therapists				
MacMillan Nurses				
Marie Curie				
Mental Health				
Occupational Therapy				
Oncology				
Palliative Care Team/Hospice				
Physiotherapy				
Psychology				
Religious and cultural				
Specialist Nurses, Continence, Lymphoedema, Breast Care				
Speech & Language Therapy				
Date:	**ACTION:**			
Crisis Management				
Is there likely to be a traumatic end e.g. bleed out, chest noises – most important to stay with the patient.				
Preparation: dark towels, work in pairs, crisis medication, sedate patient				
Date:	**ACTION:**			
Mental Health Care				
Is there a change in mental health? Consider referral for a mental health assessment (GP/Psychiatrist)				
Is there current/history of mental health difficulties?				
Would relaxation strategies be beneficial? (massage, aromatherapy, music)				
Date:	**ACTION:**			

		DATE	DATE	DATE
Agitation		/ /	/ /	/ /
Is anything physically interfering with comfort, e.g. catheter tubing, syringe driver				
Is the person in pain?				
Is the person constipated?				
Consider urine retention/catheter flowing freely				
Is the person having difficulty breathing?				
Is an infection or other change in function causing distress?				
Have there been any changes in medication?				
Could additional medication help?				
Is the person hallucinating?				
Is there a psychological or emotional cause?				
Has the person entered the “pre-active phase of dying”?				
Date:	**ACTION:**			
Liverpool Care Pathway - last 2 weeks of life				
Should Liverpool Care pathway commence?				
Date:	**ACTION:**			

PRACTICAL

	DATE	DATE	DATE
Liaison	/ /	/ /	/ /
Liaise with necessary people, e.g. GP, Palliative, District Nurses, Out of Hours, etc.			
Is Assistive Technology required ?			
Mental Capacity Act & Best Interests			
Eligibility for health funding/CHC			
Advanced statement/care planning			
Patient held records, e.g. for patients undergoing radio/chemotherapy			
Yellow folders – Devon PCT			
Plan of action for carers in event of expected death			
Consider: Out of Hours care, e.g. District Nurses, Marie Curie, Hospice at Home, Rowcroft, Devon Docs.			
Does person need Special messages/Advanced messages via their own GP			
Gold Standards Framework - GP surgery should have one - contact and ask if they should be on Register of Patients			
	DATE	**DATE**	**DATE**
Liaison continued….	/ /	/ /	/ /
Consider Resuscitation/DNAR (do not attempt resuscitation) – must be signed by GP			
Do you have access to a Palliative Community Team advice line? – Out of Hours			

Date:	**ACTION:**			

EMOTIONAL SUPPORT

	DATE	DATE	DATE
Family & siblings	/ /	/ /	/ /

What support does the family need for the individual to continue living at home e.g. invasion of own home?				
How is the family managing with feeling guilty, being able to let go, and feeling out of sequence with sibling/child dying before them?				
Does the family need additional support from others e.g. grieving/bereavement/counselling, core groups or individual support?				
Does the family need support after the event e.g. CRUSE, reflection? Ensure family have the relevant contact details.				
Date:	**ACTION:**			
		DATE	**DATE**	**DATE**
Others/friends		/ /	/ /	/ /
Informing people – does the person wish to share the news with others? Important to respect their wishes				
Who should be informed? – friends, day care, work, other professionals, e.g. GP, Nurses, CLDT				
What do we say? Use active listening skills/private room				
Preparation for loss, counselling discussion				
Marking death, e.g. prayers, flowers, memory book, photos				
Date:	**ACTION:**			
Staff support & training				
Are staff prepared for changes in care needs?				
Is additional training/support required? e.g. Breaking Bad News course				
Are supervision/core team meetings in place/required?				
De-brief in place/required. Remember peoples personal experiences of loss/lack of confidence have an effect on ability to care				
Crisis management/foreseeable crisis – are clear guidelines in place?				
Are all staff aware/understand individualised End of Life Plan				
Date:	**ACTION:**			

Change of accommodation				
Is the current accommodation suitable?				
Is additional support required to remain in their home?				
Does the person require – nursing home, hospital, hospice or residential care?				
Consider effects of change on all concerned, e.g. family, other residents				
Liaison with social care regarding funding				
Date:	**ACTION:**			
		DATE	**DATE**	**DATE**
End of Life Plan		/ /	/ /	/ /
Following diagnosis, initiate discussion regarding:				
Who do they want to involve in their End of Life Plan				
Does the person work? Do they need additional support to maintain doing the things they like?				
Where do they wish to be cared for – preferred place, if possible				
Life book/reminiscences				
Memory box				
Objects of comfort				
Are there things they would like to do before dying, e.g. Wish List				
Do they wish to plan their funeral, music, memorials?				
Wills				
Organ donation (use discretion)				
Date:	**ACTION:**			
Culture/Religion				
Establish religious beliefs from person/family				
Do they wish to access a place of worship?				
If preferred, arrange for priest or other religious				

representatives to visit				
Establish cultural traditions and preferences re gender roles, diet, bodily functions, expressing grief.				
Date:	**ACTION:**			

Websites:

www.ageconcern.org.uk
Age Concern – Charity providing advice about end-of-life issues

www.bapen.org.uk
Malnutrition Universal Screening Tool (M.U.S.T.)

www.bild.org.uk
British Institute of Learning Disabilities

www.cancerbackup.org.uk
Cancerbackup – Charity providing advice and publications about end-of-life issues; merged with Macmillan in 2008

www.crusebereavementcare.org.uk
Cruse Bereavement Care – National charity that offers help to bereaved people

www.devonpartnershiptrust.nhs.uk
Devon Partnerhship Trust

www.dh.gov.uk
Department of Health – source various publications, such as:

- /Mental Capacity Act 2005
- /publicationsandstatistics /DH_103162
  Continuing Healthcare Framework – Healthcare funding

www.direct.gov.uk
Official UK Government website

www.disdat.co.uk
DisDAT – Disability Distress Assessment Tool

www.easyhealth.org.uk
Easy Health – Health information that is easy to understand

www.endoflifecareforadults.nhs.uk
National End-of-Life Care Programme

www.goldstandardsframework.nhs.uk
Gold Standards Frameworks – Helpline and Central Team – 01922 604 666

www.helptheaged.org.uk
Help the Aged – Advice about planning for the end of life and bereavement

www.helpthehospices.org.uk
Hospice Information Service – Information about local hospices – 020 7520 8200

www.learningdisabilities.org.uk
Foundation for People with Learning Disabilities

www.learningdisabilitycancer.org.uk
Easy read information, supported by Plymouth Hospitals

www.mcpcil.org.uk
Liverpool Care Pathway

www.macmillan.org.uk
Macmillan Cancer Support – Charity providing information and emotional support for people with a life-limiting illness and for healthcare workers – 0808 808 0000

www.mariecurie.org.uk
Marie Curie Cancer Care – Charity providing information, advice and nursing services – 0800 716 146

www.ncpc.org.uk
National Council for Palliative Care – Umbrella organisation for those involved in providing, commissioning and using palliative care services

www.naturaldeath.org.uk
Natural Death Centre – Advice for people who want an environmentally friendly funeral – 0871 228 2098

www.nice.org.uk
National Institute for Health and Clinical Excellence

www.valuingpeople.gov.uk
Valuing People Now

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info@pcpld.org
Palliative Care for People with Learning Disability Network

Resources:

Remember information packs/appropriate literature, such as:

- Information Packs, e.g. Macmillan Cancer Support, Palliative Care Education Pack, Marie Curie – End of Life Care The Facts
- Appropriate literature, e.g. BACCUP book, hospital booklets/leaflets

- Easy read information, e.g. Books Beyond Words, Story Books, Mencap Living and Dying with Dignity
- Story books/talking mats around end of life journey in context of illness

Also remember your local Cancer Information Centre and Hospital Library.

Glossary:

Advanced Statement/Care Planning: Document/Process of discussing and planning ahead, e.g. in anticipation of some deterioration in a patient's condition

Anticipatory Medicine: Prescribed medication which may be requested and stored, in advance, if it is felt the person may soon require, e.g. pain relief, anti-emetic

Assistive Technology: Technology and services that meet people's requirements to live independently

BACCUP: Publications about end of life issues

Baseline Changes: Has there been any deterioration or improvement to the person's norm.

CHC: Continuing Health Care – A complete package of ongoing care arranged and funded solely by the NHS, where it has been assessed that the individual's primary need is a health need.

Compliance: The extent to which a patient takes, or does not take, medicines as prescribed

Concordance: An agreement between patient and health professional regarding the provision of care. Concordance and compliance are frequently used interchangeably

Devon Docs: Local Out of Hours GP service

Devon PCT: Devon Primary Care Trust

Dictaphone: A useful tool for recording consultations so that they may be listened to at another time

DISDAT: Disability Distress Assessment Tool

DLA: Disability Living Allowance

Emergency Medicine: Controlled medication, kept in the home, for use by GP or District Nurse

Gold Standards Framework: Identifies people who are in need of palliative care. Offers practical, step-by-step system, to improve the organisation of care for dying people

Invasion: To be aware of carers/persons feelings of intrusion around their home and personal life

Liverpool Care Pathway: A framework that provides guidance for health professionals to follow in the last days or hours of a person's life

Lymphoedema: A condition of localised fluid retention and tissue swelling caused by a compromised lymphatic system

MacMillan Nurses: Provide information, support and advice to people with life-limiting illnesses and their families. Provide support in managing pain and other symptoms.

Marie Curie: Provide information and day/night care for people with life-limiting illnesses being cared for at home

Mental Capacity Act & Best Interests: The ability to make a decision about a particular matter at the time the decision needs to be made. Review this frequently – not just one assessment

M.U.S.T.: Malnutrition Universal Screening Tool

Personalised Eating Plan: Helps to plan and assess your food choices

Pre active Phase of Dying: May cause terminal agitation – a major distressful symptom in the dying

Prescribing Boxes: Plan ahead/anticipate future medication needs

PRN: As and when required

Register of Patients: Communication and planning around end of life in last 12 months. Person discussed regularly at GP meetings – at least every 3 months

Resuscitation/DNAR: Do not attempt to resuscitate – the End of Life Special Message Form - must be signed by GP

Rowcroft: Local Hospice

Special Messages: Information on GP system, such as: medical conditions, who to alert, whether the person is violent or any other special need, that can be accessed by colleagues who are working out-of-hours and are unfamiliar with the patient

Supplementary Foods: A nutritional supplement to an ordinary diet to give you the best possible health protection

Talking Mats: A low tech interactive communication resource to help people express views and feelings

Task Management: Structuring and pacing your day/activities

Waterlow Score: Gives an estimated risk of a patient developing a pressure sore

Yellow Folders: District Nurse Care Planning folder, kept in the home.

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