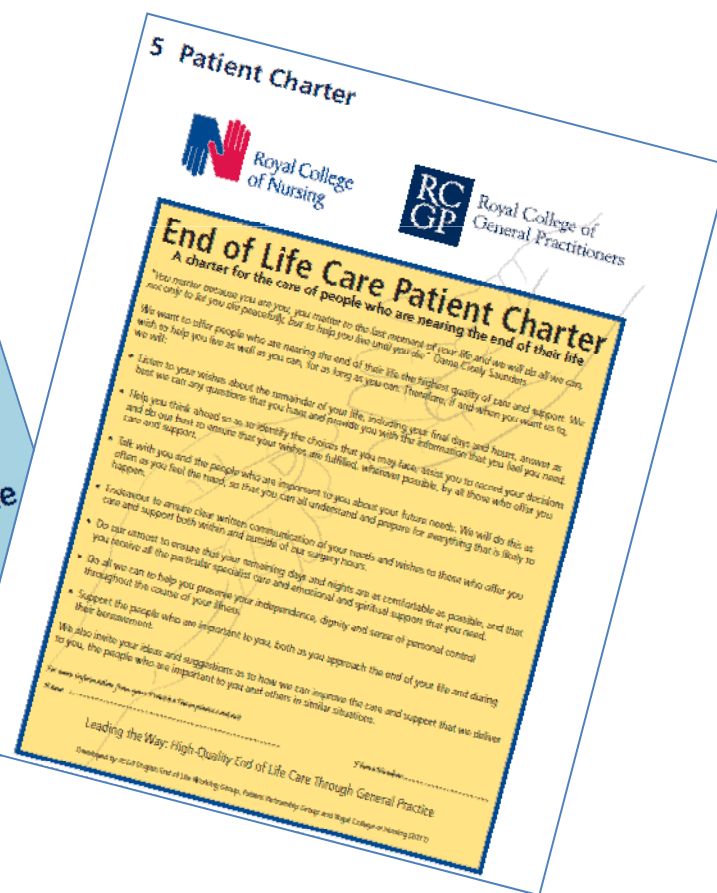
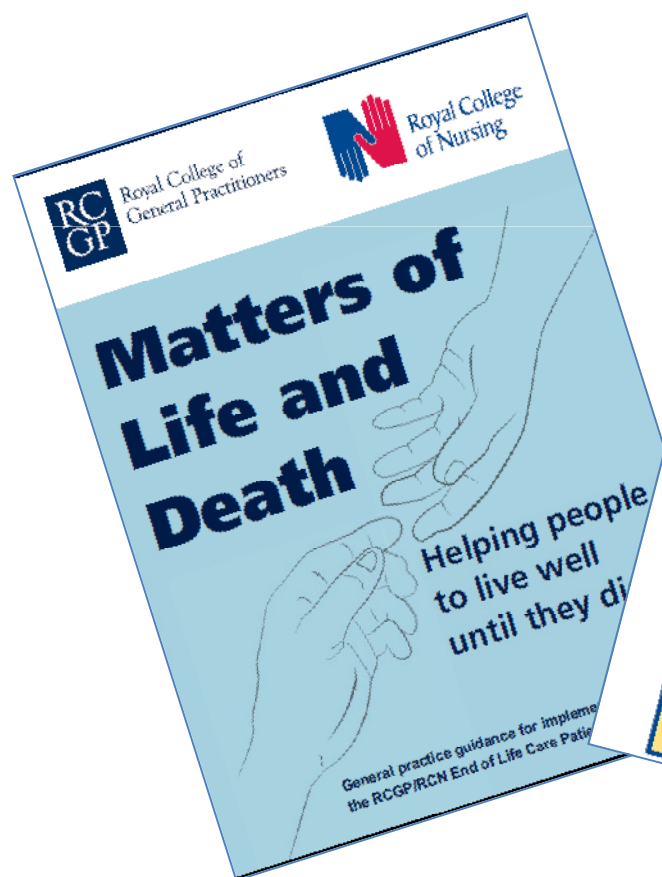


Quality Care: Our Role is to help people live well, until they die.



Aim to Consider:

- Holistic assessment and managing pain and other symptoms for people with a learning disability
- Holistic Care and Support
- Ethical Decision making



Fundamentally EoLC = Support?

- The 'six dimensions of the supportive role':
 - To value patients as individuals
 - To connect
 - To empower
 - To do for,
 - To find meaning
 - Assist individuals to 'preserve their own integrity'.

Davies & Oberles (1990)

Support in Practice

- Encourage individuals to:
 - utilise own coping strategies
 - set priorities
 - focus on good things
 - be flexible in achieving ambitions
 - reorganise daily activities
 - be as independent as possible.
- Be alongside - Be there and listen
- Reduce anxieties - promote calm
- Follow a person-centred approach



Person-centred assessments

- If we are going to produce person-centred plans, assessments need to be person-centred
- People who do assessments need to think about these questions:

Person-centred assessments

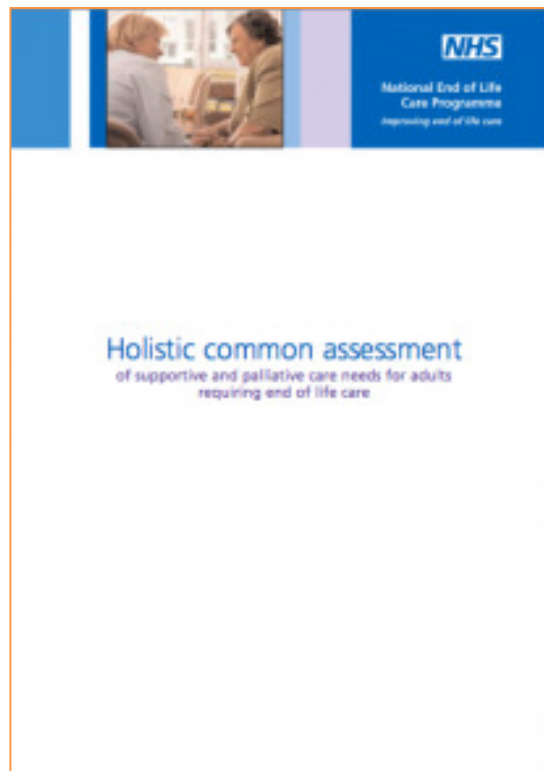
- Which assessments do I do?
- Why do I do them?
- What information do my assessments produce?
- Does that information help the person I am working with to get the life they want now and in the future?

people ● lives ● communities



- What aspects should I be considering with regards EoL care needs?

Assess, Monitor, Care



**Physical,
Psychological,
Social,
Spiritual
Cultural,
Environmental,
and Financial**

Tools to help us Assess needs



Barthel Index

A

Task	With help	Independent
Feeding	5	10
Moving from wheelchair to bed	5-10	15
Personal toilet (wash, shave, comb)	0	5
Getting on / off toilet	5	10
Bathing	0	5
Walking on level surface	10	15
Ascend, descend stairs	5	10
Dressing	5	10
Controlling bowels	5	10
Controlling bladder	5	10

B

FEEDING

- 0 = unable
- 1 = needs help cutting, spreading butter, etc., or requires modified diet
- 2 = independent

BATHING

- 0 = dependent
- 1 = independent (or in shower)

GROOMING

- 0 = needs to help with personal care
- 1 = independent face/hair/teeth/shaving (implements provided)

DRESSING

- 0 = dependent
- 1 = needs help but can do about half unaided
- 2 = independent (including buttons, zips, laces, etc.)

BOWELS

- 0 = incontinent (or needs to be given enemas)
- 1 = occasional accident
- 2 = continent

BLADDER

- 0 = incontinent, or catheterized and unable to manage alone
- 1 = occasional accident
- 2 = continent

TOILET USE

- 0 = dependent
- 1 = needs some help, but can do something alone
- 2 = independent (on and off, dressing, wiping)

TRANSFERS (BED TO CHAIR AND BACK)

- 0 = unable, no sitting balance
- 1 = major help (one or two people, physical), can sit
- 2 = minor help (verbal or physical)
- 3 = independent

MOBILITY (ON LEVEL SURFACES)

- 0 = immobile or < 50 yards
- 1 = wheelchair independent, including corners, > 50 yards
- 2 = walks with help of one person (verbal or physical) > 50 yards
- 3 = independent (but may use any aid; for example, stick) > 50 yards

STAIRS

- 0 = unable
- 1 = needs help (verbal, physical, carrying aid)
- 2 = independent

C

	No attempt	Attempts	Some help	Minimal help	Independent
Personal Hygiene	0	1	3	4	5
Bathing	0	1	3	4	5
Feeding	0	2	5	8	10
Toileting	0	2	5	8	10
Stair climbing	0	2	5	8	10
Dressing	0	2	5	8	10
Bowel control	0	2	5	8	10
Bladder control	0	2	5	8	10
Bed to chair transfer	0	3	8	12	15
Ambulation	0	3	8	12	15

D

Task	Dependent		Independent	
	Intact	Limited	Helper	Null
Drinks from cup/ feed from dish	0	0	5	10
Dress upper body	0	0	3	5
Dress lower body	0	2	5	5
Don brace or prosthesis	-2	-2	0	0
Grooming	0	0	5	5
Wash or bathe	0	0	4	4
Bladder continence	0	5	10	10
Bowel continence	0	5	10	10
Care of perineum/clothing at toilet	0	2	4	4
Transfer chair	0	7	15	15
Transfer toilet	0	3	5	6
Transfer tub or shower	0	0	1	1
Walk on level 50 yards	0	10	15	15
Up and down stairs for one flight	0	5	10	10
Wheelchair 50 yards if not walking	0	0	5	15

How would I know?

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6.

Name of resident: _____

Name of person completing the scale: _____

Designation of person completing the scale: _____

Date: _____ Time: _____

Latest pain relief given was _____ at _____ hrs

Q1. VOCALISATION
eg whimpering, groaning, crying
Absent 0 Mild 1 Moderate 2 Severe 3 Q1

Q2. FACIAL EXPRESSION
eg looking tense, frowning, grimacing, looking frightened
Absent 0 Mild 1 Moderate 2 Severe 3 Q2

Q3. CHANGE IN BODY LANGUAGE
eg fidgeting, rocking, guarding part of body, withdrawn
Absent 0 Mild 1 Moderate 2 Severe 3 Q3

Q4. BEHAVIOURAL CHANGE
eg increased confusion, refusing to eat, alteration in usual patterns
Absent 0 Mild 1 Moderate 2 Severe 3 Q4

Q5. PHYSIOLOGICAL CHANGE
eg temperature, pulse or blood pressure outside normal limits
Absent 0 Mild 1 Moderate 2 Severe 3 Q5

Q6. PHYSICAL CHANGES
eg skin tears, pressure areas, arthritis, contractures, previous injuries
Absent 0 Mild 1 Moderate 2 Severe 3 Q6

Add scores for 1-6 and record here Total pain score

Now tick the box that matches the Total Pain Score

0 - 2 No pain	3 - 7 Mild	8 - 13 Moderate	14+ Severe
------------------	---------------	--------------------	---------------

Finally, tick the box which matches the type of pain

Chronic	Acute	Acute on Chronic
---------	-------	------------------

Abbey, J, De Bellis, A, Piller, N, Esterman, A, Giles, L, Parker, D and Lowrey, B.
Funded by the JH & JD Gunn Medical Research Foundation 1998 - 2002.
(This document may be reproduced with this acknowledgement retained).

CHANGE PAIN

Supplied by Grünenthal Ltd.

Disability

Distress Assessment Tool



Client's name: _____
DOB: _____ Gender: _____
Unit/ward: _____ NHS No: _____

Your name: _____ Date completed: _____

Name of others who helped complete this form: _____

DisDAT is
intended to help identify distress cues in people who because of cognitive impairment or physical illness have severely limited communication.

Designed to describe a person's usual content cues, this enabling distress cues to be identified more clearly.

NOT a scoring tool. It documents what many staff have done instinctively for many years that providing a record against which subtle changes can be compared. This information can be transferred with the client or patient's family involvement.

Only the first step. Once Distress has been identified the usual distress decisions have to be made by professionals.

Meant to help you see your client or patient. It gives you more confidence in the observation skills you already have which in turn will help you improve the care of your client or patient.

INSTRUCTIONS FOR USING DisDAT ARE ON THE BACK PAGE

SUMMARY OF SIGNS AND BEHAVIOURS

Appearance when CONTENT Face Tongue/lips Skin Eyes	Appearance when DISTRESSED Face Tongue/lips Skin Eyes
---	--

Vocal signs when CONTENT Sounds Speech	Vocal signs when DISTRESSED Sounds Speech
---	--

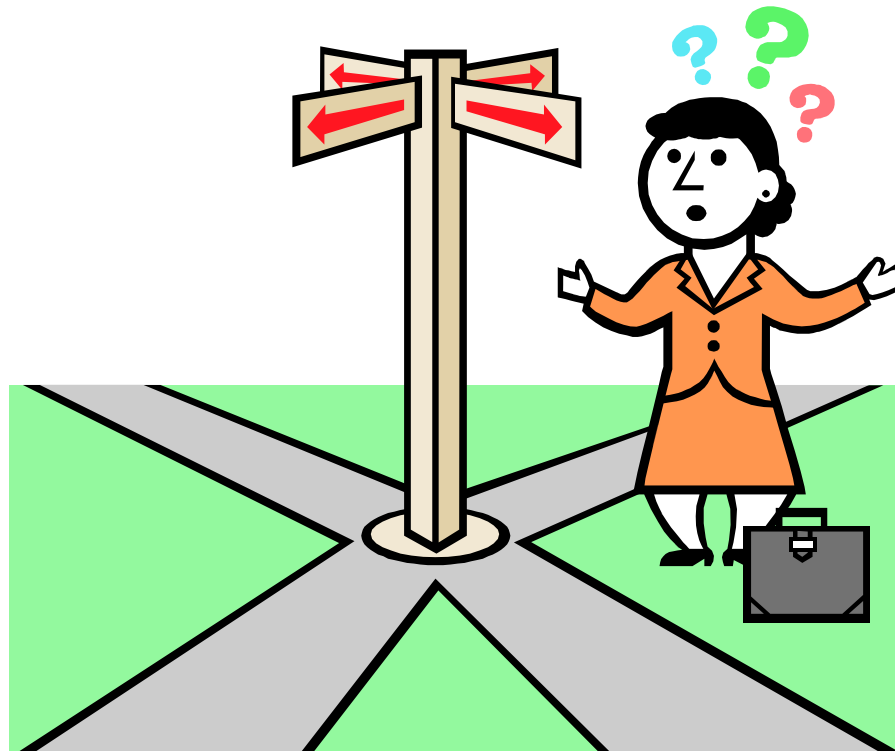
Posture and movements when CONTENT Posture Movements Comfortable distance	Posture and movements when DISTRESSED Posture Movements Comfortable distance
---	--

Posture & observations when CONTENT Posture Observations	Posture & observations when DISTRESSED Posture Observations
---	--

Known triggers of distress (write here any actions or situations that usually cause or worsen distress)

DisDAT © 2008 Keelepain & Keele NHS Trust and Dr. Oswald's Hospice

Ethical Issues in Palliative and End of Life Care



What do we mean by Ethics?

The rights or wrongs of human
behaviour and the motives
behind the behaviour

Your decisions/judgement will
depend upon your values
and value systems.

Core Ethical Values

- Honesty
- Integrity
- Fairness
- Trustworthiness
- Respect
- Responsibility
- Accountability
- Being a good citizen
- Patient / Client Welfare
- Excellence in Health / Social -care Delivery

Professional Ethical Code

Based on principles which are used to guide our decisions and judge our behavior but also bring our own values to the equation.

Four Key Ethical Principles

- Beneficence
- Maleficence v Non-Maleficence
- Justice
- Autonomy

Ethical Practice

Equates to the balance between
all four principles

Beneficence

- To act in the best interest of others.
- To contribute to others welfare
- Act as Patients advocate
- Report Concerns to able other

Maleficence

To Do Harm with intent

Non-Maleficence

Doing no harm

Justice

- A respect for the patients rights?
- But what about our rights and families rights?
- What is Just?

Autonomy

- The Patients, Staff, Family right to make their own decisions

Ethical Viewpoint

Not just a matter of opinion but
requires reasoned and rational
thinking

Ethical Dilemma

This occurs when two or more principles conflict with each other.

Palliative Care Dilemmas

- Withdrawal of treatment
- Hydration
- Sedation
- Living Wills - Advanced Directives
- Assisted Suicide & Euthanasia
- Research

Case Studies

