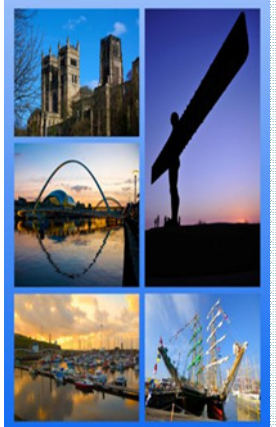
www.noeccn.org.uk

NoECCN

North of England Critical Care Network



"Dignified Death" Communicating the Priorities

Julie Platten

Network Manager

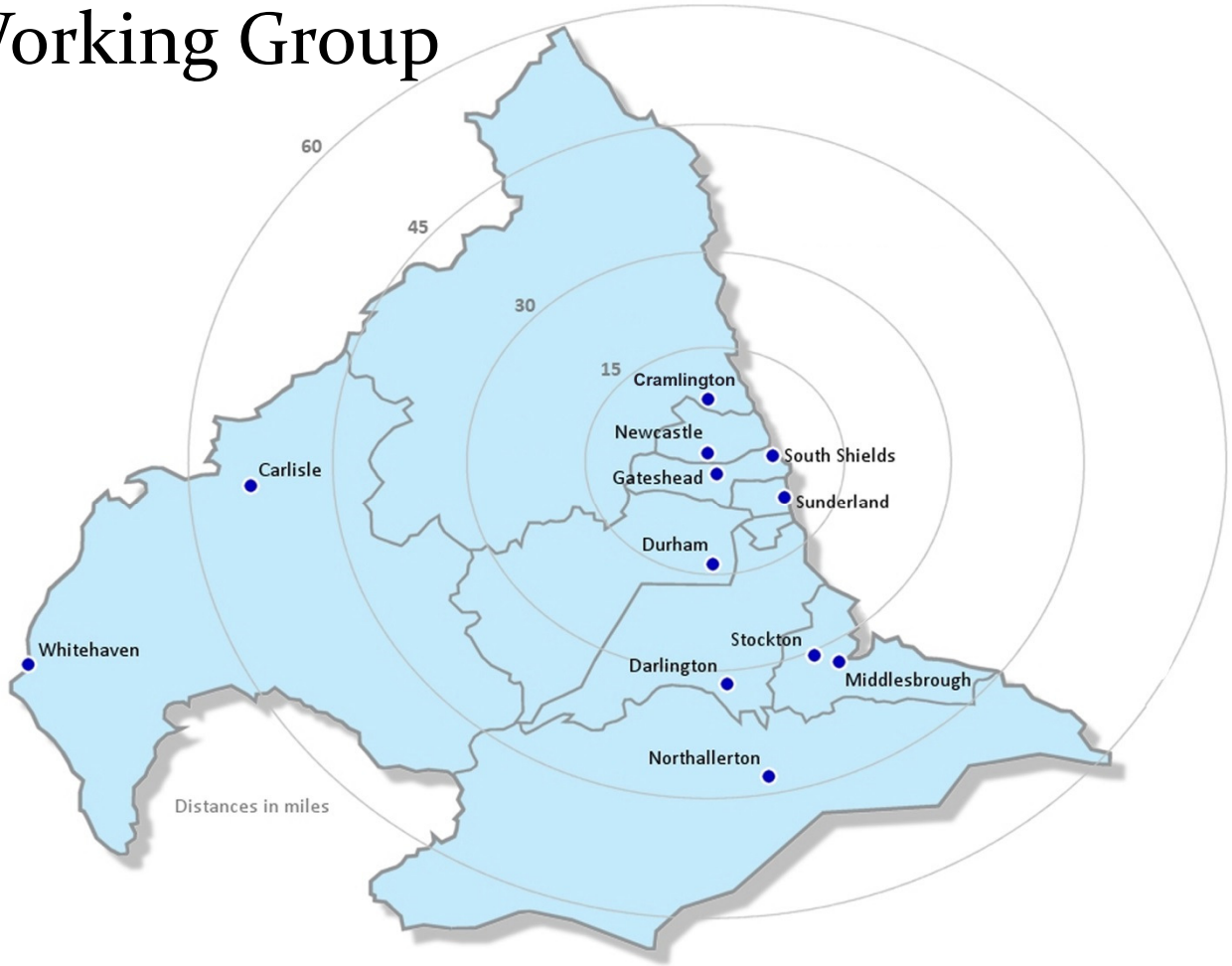
On behalf of the North of England Critical Care Network End of Life Working Group

" How people die remains in the memory of those that live on."

Dame Cicely Saunders, 2014

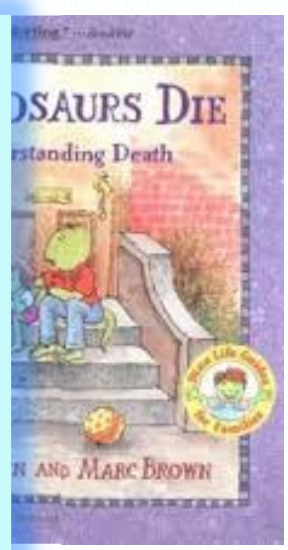
North of England Critical Care Network

End of Life Working Group



When tomorrow starts without me,
and I'm not here to see
If the sun should rise and find your
eyes, filled with tears for me
I wish so much you wouldn't cry
the way you did today.
while thinking of the many things
we didn't get to say.

I know how much you love me
as much as I love you.
And each time you think of me,
I know you'll miss me too.
When tomorrow starts without me
don't think we're far apart
or every time you think of me
I'm right there in your heart




HOSPITALS BRIBED TO PUT PATIENTS ON PATHWAY TO DEATH


ARE THEY PLAYING GOD?


Top doctor's chilling claim: The NHS kills off 130,000 elderly patients every year

Professor Patrick Pullicino in the Daily Mail on June 20


EX-NURSE: I FOUND OUT THEY WERE LETTING MY MUM DIE ONLY WHEN I READ HER NOTES

By John Stevens

A FORMER nurse last night told how she found out her mother was being allowed to die only by reading her medical notes.

The hospital apologised and said it would launch an investigation after Jane Taylor, 57, said she discovered doctors had sedated her mother and withdrawn foods and fluids when she caught a glance of her medical notes, which had been left on a window sill.

But it was too late to stop the process and her 83-year-old mother died.

Phyllis Nichols was admitted to Epsom Hospital in Surrey in May 2011 with a urinary tract infection.

Mrs Taylor says the health of her mother, who had been an active member of her local church and a skilled gardener, seemed to improve as she responded well to treatment. However, she deteriorated after doctors removed a fluids drip.

Mrs Taylor said: 'One day I found her moved to a side room with a morphine pump. Her notes, which were usually

LIVERPOOL Care Pathway

Promoting best practice for care of the dying


Daily Mail

Will 2013 be the year of the silliest hats ever?

60,000 PUT ON DEATH PATHWAY WITHOUT BEING TOLD


HOW SCANDAL HAS GROWN

DOCTORS TO ACT ON CARE PATHWAY

Mail yesterday

Family revive father doctors ruled wasn't worth saying

October 13

Son calls police over mother's death on the 'care pathway'

October 10

Care? No, this is a pathway to killing

October 15

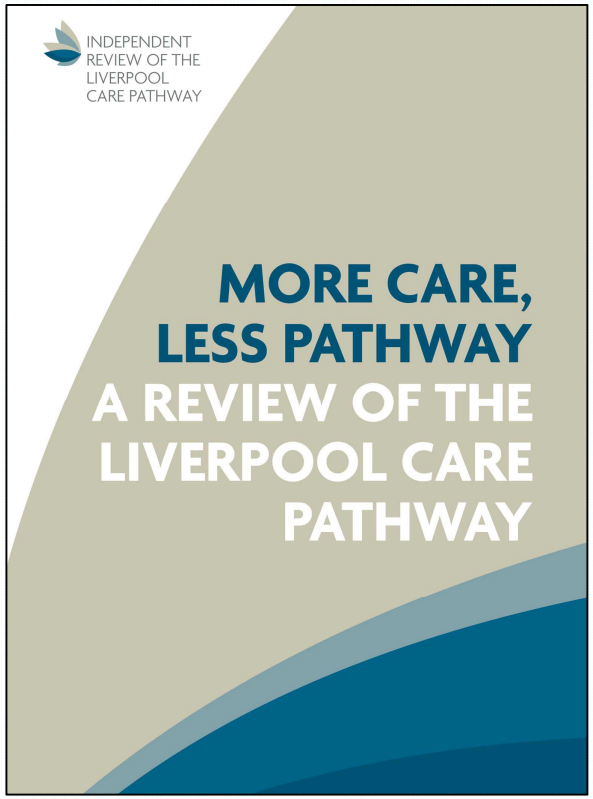
'IT'S A MASSIVE COVER-UP'

ELSIE Devine, 88, was receiving respite care following treatment for a urinary tract infection.

Four weeks into her six-week hospital stay, in November 1999, she was given a cocktail of drugs including painkiller Fentanyl, sedative Midazolam and four times the recommended dose of diamorphine.

She received a 'substantial overdose' of oplates, dying 58 hours later. Her daughter Ann Reeves, 56, a beauty therapist, said: 'My mother was getting better until she went into that place. We are in no doubt there has been a massive cover-up.'

Mrs Reeves has launched a petition calling for 'Elsie's Law', which would ban a doctor giving diamorphine without the signed consent of the patient or a relative.

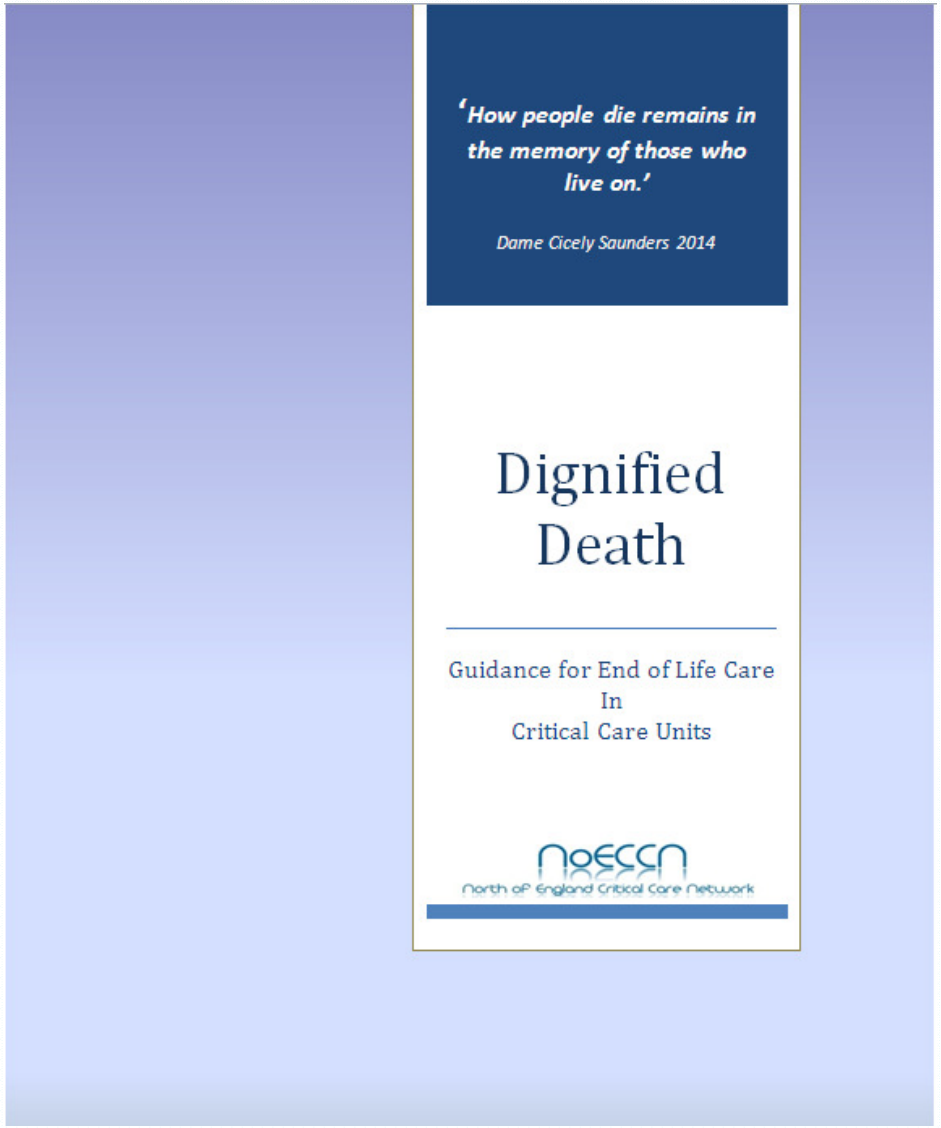


Independent review by Neuberger (2012)

Leadership Alliance for the Care of Dying People (LACDP) 2014

Identified Key Priorities

Recognise	The possibility that the person is dying is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly
Communication	Sensitive communication takes place between staff and the dying person, and those identified as important to them
Involve	The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the patient wants
Support	The needs of the families and others identified as important to the dying person are actively explored, respected and met as far as possible
Plan & Do	An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion


'How people die remains in the memory of those who live on.'
Dame Cicely Saunders 2014
Dignified Death
Guidance for End of Life Care
In
Critical Care Units
North of England Critical Care Network

Name: Hospital Number: Date:

MDT Decision / Diagnosing Dying

	YES	NO
Would Intravenous therapy be an appropriate treatment?		
If NO-why?		
Would enteral nutrition be an appropriate treatment?		
If NO-why?		
Would oral antibiotics be an appropriate therapy?		
If NO-why?		
Would intravenous antibiotics be an appropriate therapy?		
If NO-why?		
Would physiotherapy be an appropriate therapy?		
If NO-why?		
Would blood transfusion be an appropriate treatment?		
If NO-why?		
Would cardiovascular support with inotropes be an appropriate therapy?		
If NO-why?		
Would non-invasive ventilation be an appropriate therapy?		
If NO-why?		
Would invasive ventilation be an appropriate therapy?		
If NO-why?		
Would renal replacement therapy be an appropriate therapy?		
If NO-why?		
Would it be appropriate to defibrillate a "shockable" dysrhythmia in a monitored patient?		
If NO-why?		
Would CPR be an appropriate treatment?		
If NO-why?		
IS THIS PATIENT FOR A CARDIAC ARREST CALL?		
If NO, please complete a DNACPR form and file in the notes with discussion with the patient / family		
IS THE PATIENT IN THE LAST FEW DAYS / HOURS OF LIFE?		
If YES – commence GUIDELINES FOR END OF LIFE CARE If NO – review form daily or if the clinical condition alters or the patient views are changed		

Signature	Print Name	Position	GMC
Date	Time	Review Date	Time

Decisions reviewed: reconfirmation/cancelled/changed –if changed complete new form

Signed	Print Name	Date	Time

Name: Hospital Number: Date:

Initial Assessment (joint assessment by doctor and nurse)

DIAGNOSIS & BASELINE INFORMATION

Diagnosed as in last few days / hours of life by : (Name)

DOB: M/F: Ethnicity:

At the time of assessment is the patient:

	Y	N
In pain		
Agitated		
Vomiting		
Dyspnoeic		
Restless		
Distressed		
UTI problems		

	Y	N
Able to swallow		
Continent (bladder)		
Catheterised		
Continent (bowels)		
Constipated		
Aware		

	Y	N
Confused		
(Record below which is applicable)		
Conscious		
Semi-conscious		
Unconscious		
Intubated		
Respiratory Support		
Ventilated		
CPAP		
BIPAP (NIV)		
Face Mask		
Other:		

Experiencing respiratory tract secretions		
Experiencing other symptoms (e.g. oedema, itch)		

COMMUNICATION

	Y	N
The patient is able to take a full and active part in communication		
If NO –why?		

First Language: Interpreter Y/N –Contact Number:

Does the patient have:	Y	N
An Advanced Care Plan		
An Advanced decision to refuse treatment (ADRT)		
Does the patient have the capacity to make their own decisions at this moment in time?		

If NO - Consider the support of an IMCA –please document below.

Name: Contact details:

The relative/carer is able to take a full and active part in communication		
If NO –why?		
The patient is aware that they are dying?		
Comment:		
The relative or carer is aware that they are dying.		
Comment		
Specialist Nurse for Organ Donation has been contacted?		
Comment		
Explored preferred place of death – if wish to go home refer to Discharge Home to Die Guidelines		
Comment		

Contact information:

1st Contact:	At any time		Not at Night-time	
Relationship	Telephone		Mobile	
2nd Contact:	At any time		Not at Night-time	
Relationship	Telephone		Mobile	

N:O:K: - if different from above.

Name: Contact Number:

Name: Hospital Number: Date:

FACILITIES

	Y	N
The relative/ carer have had a full explanation for the facilities available to them and have been given the visitor information. (Car parking / beverages / accommodation)		

Comment:

SPIRITUALITY

	Y	N
The opportunity is given to patient / carers discuss what is important to them. (wishes, feelings, faith, values, organ donation) These are respected as far as practically possible.		

Comment:

Religion identified: Chaplaincy Service offered:

External support: Name: Contact No: Date:

Comment:

Needs now:

Needs at death:

Needs after death:

MEDICATION

The patient has medication prescribed on a prn basis for the following symptoms which may develop in the last hours of life.		
Pain		Comment:
Agitation		
Respiratory tract secretions		
Nausea / vomiting		
Dyspnoea		

Ensure the following is explained:

- The patient is only receiving medication that the MDT agrees is beneficial at the time.
- Anticipatory prescribing in this manner will ensure that there is no delay in responding to a symptom if it occurs.
- Medicines for symptom control will only be given when needed, at the time and just enough and no more than is needed to help the symptom.
- That when new medication is commenced (especially via infusion) rationale for this will be explained.

Comment:

Dignified Death DD2 Working Version 08/07/2015 NoECCN

Name: Hospital Number: Date:

Current Interventions

The patient's current interventions has been reviewed by the MDT and discussed with the patient, relatives/carer.	Y	N

Comment

	Currently not being taken / or given / or in place	Discontinued	Continued	Commenced
Routine Blood Tests				
Intravenous Antibiotics				
Blood Glucose Monitoring				
Recording of routine vital signs				
Oxygen therapy				
Physiotherapy				
I.V. vasoactive medications				
Electronic Monitoring /alarms				
Renal Replacement Therapy				
NG tube (gastric secretions)				
Current ventilatory support				

Current ventilator support:

Changes:

Silence alarms (remember apnoea alarm)

Comment:

Has patient has a DNACPR in place	YES		NO	
This has been explained and discussed with patient, relative or carer.	YES		NO	

Please complete the appropriate associated documentation according to the policy and procedure.
Comment:

Implantable Cardiovertor Defibrillator (ICD) is deactivated	YES		NO	
This has been explained and discussed with patient, relative or carer.	YES		NO	

Contact patient's cardiologist. Refer to the ECG technician and refer to local/regional – policy and procedure
Comment

Nutrition

The need for clinically assisted (artificial) nutrition is reviewed by MDT	YES		NO	

Comment:

Decision discussed with patient / relative / carer.	YES		NO	

Name: Hospital Number: Date:

Hydration

The need for clinically assisted (artificial) hydration is reviewed by MDT	YES		NO	

Comment:

Decision discussed with patient / relative / carer.	YES		NO	

Skin Care

The patient's skin integrity is assessed	YES		NO	

Risk Assessment score:				
Existing Pressure damage	YES		NO	
Mattress in use / type				
Frequency of positional changes				

Comment:

Explanation of Care

A full explanation of plan of care is explained to the patient.	YES		NO	

Comment:

A full explanation of plan of care is given to the relative / carer	YES		NO	

Name of relative(s) / Carer (s) present	Relationship to patient
Names of Healthcare professional present:	Position

Comment:

Communication log commenced and left at the patient's bedside	YES		NO	

Comment:

The patient's primary health care team / GP practice is notified that the patient is dying.	YES		NO	

Comment:

Please sign on completion of the initial assessment

Signature

Doctor's Name:		Nurse's Name:	
Position:		Position:	
Signature:		Signature:	
Bleep:		Extension Number:	
Date:		Date:	
Time:		Time:	

Dignified Death DD2 Working Version 08/07/2015 NoECCN

Name: Hospital Number: Date:

ONGOING ASSESSMENT OF THE PLAN OF CARE

UNDERTAKE A MDT ASSESSEMENT & REVIEW THE CURRENT CARE PLAN IF:

Improved conscious level, vital signs, functional ability, oral intake, mobility, ability to perform self-care

AND / OR

Concerns expressed regarding management plan from patient, relative /carer or team

AND / OR

It is 24 hours since last full MDT assessment

PLANNED CARE SHOULD BE ASSESSED AT LEAST 4 HOURLY

	ASSESSMENT	COMMENT
A	The patient has pain	Verbalised by the patient if conscious, pain free on movement. Observe for non-verbal clues. Consider need for positional change. Use pain assessment tool if appropriate. Consider PRN analgesia for incident pain
B	The patient is agitated	Patient does not display any signs of restlessness or distress, exclude reversible causes e.g. retention of urine, opioid toxicity
C	The patient does has respiratory tract secretions	Consider positional change. Discuss symptoms and plan of care with relative / carer. Medication to be given as soon as symptom occurs
D	The patient does have nausea	Verbalised by the patient if conscious
E	The patient is vomiting	Give medication as prescribed
F	The patient is receiving planned respiratory support	Monitor for signs of distress/ breathlessness. Amend the mode of basic or advanced respiratory support given as appropriate. Explain to the relative / carer.
G	The patient does have urinary problems	If catheterised is it patent and draining
H	The patient does have bowel problems	Monitor constipation / diarrhoea. Monitor skin integrity.
I	Medication is administered safely	Monitoring sheet for infusions. The patient is only receiving medication that is beneficial at this time.
J	The patient is receiving fluids as planned	The patient is supported to take oral fluids / thickened fluids for as long as tolerated. Monitor for signs of aspiration / distress. Consider IV therapy if in the patients best interest – if in place monitor and review rate / volume. Discuss with relative / carer
K	The patient is moist and clean	Adhere to mouth care policy. Relative / carer involved in care giving as appropriate.
L	The patient skin integrity is maintained	Assessment, cleansing, positioning, use of special aids (mattress / bed). Frequency of repositioning according to patients individual needs
M	The patients personal hygiene needs are met	Skin care, eye care, change of clothing according to individual needs. Relative / carer involved in care giving as appropriate.
N	Appropriate physical environment	Side ward if available. Well-fitting curtains, sufficient space at the bed side, silence / music, light / dark, nurse call bell available
O	Psychological well-being maintained	Staff just being at the bed side can be seen as a sign of support. Respectful, verbal and non-verbal communication, use of listening skills, information and explanation of care given. Use of communication log. Spiritual / religious / cultural needs – consider use of the chaplaincy team.
P	Relative / Carer well-being maintained	Just being at the bedside can be seen as a sign of support and caring. Consider spiritual / religious / cultural needs, expressions may be unfamiliar to the healthcare professional but normal for the relative / carer. Listen and respond to worries / fears. Consider physical

TIME / DATE:

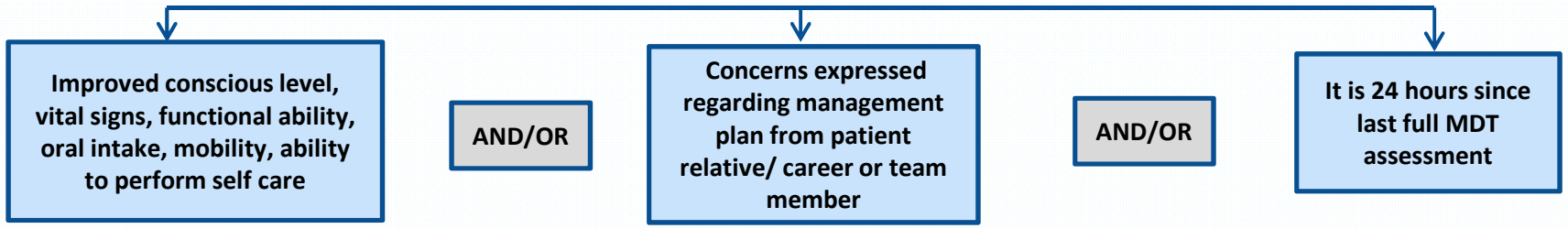
Code	Yes	No	Comment
A			
B			
C			
D			
E			
F			
G			
H			
I			
J			
K			
L			
M			
N			
O			
P			

SIGN:

Name: Hospital Number: Date:

ONGOING ASSESSMENT OF THE PLAN OF CARE

UNDERTAKE A MDT ASSESSMENT & REVIEW CURRENT CARE PLAN IF:



Name: Hospital Number: Date:

MDT Daily Full Assessment

DIAGNOSIS & BASELINE INFORMATION

Diagnosed as in last few days / hours of life by: (Name)

At the time of assessment is the patient:

	Y	N
In pain		
Agitated		
Vomiting		
Dyspnoeic		
Restless		
Distressed		
UTI problems		

	Y	N
Able to swallow		
Continent (bladder)		
Catheterised		
Continent (bowels)		
Constipated		
Aware		

	Y	N
Confused		
(Record below which is applicable)		
Conscious		
Semi-conscious		
Unconscious		
Intubated		
Respiratory Support		
Ventilated		
CPAP		
BiPAP (NIV)		
Face Mask		
Other:		

Experiencing respiratory tract secretions		
Experiencing other symptoms (e.g. oedema, itch)		

CURRENT INTERVENTIONS

	Currently not being taken / or given / or in place	Discontinued	Continued	Commenced
Routine Blood Tests				
Intravenous Antibiotics				
Blood Glucose Monitoring				
Recording of routine vital signs				
Oxygen therapy				
Physiotherapy				
I.V. vasoactive medications				
Electronic Monitoring /alarms				
Renal Replacement Therapy				
NG tube (gastric secretions)				
Artificial Nutrition				
Artificial Hydration				
Current ventilatory support				

Changes:

Silence alarms (remember apnoea alarm)

Comment:

PLAN OF CARE

Plan:

Healthcare professionals:

- Record any conversations / discussions that you have with the patient, relative or carer.
- Do not use medical terminology

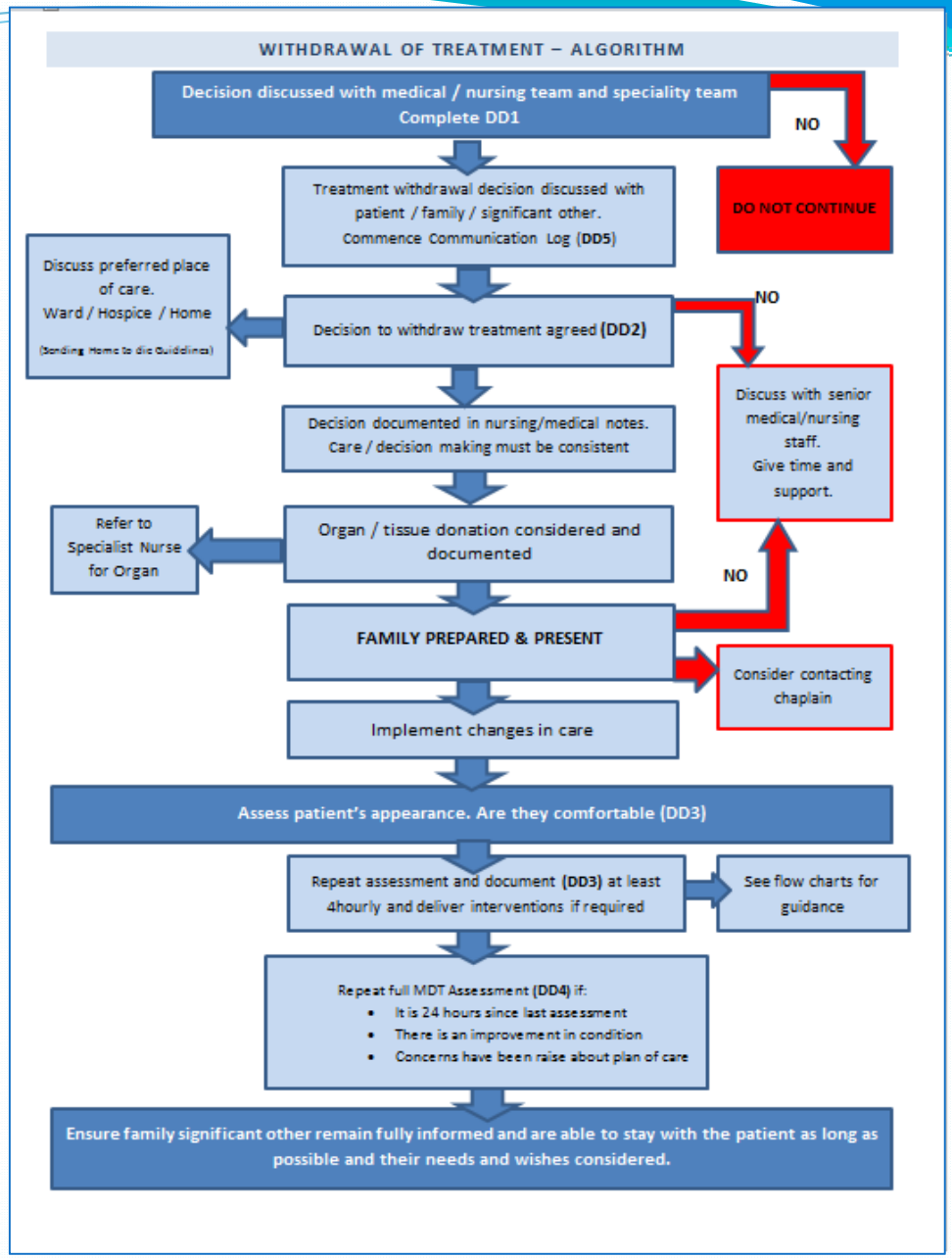
Patient / relative / carer

- Used to recap information that you have just been given, helps you to process it in your own time
- Allows other family members to see what has been said
- Allows you record any questions you may like to ask but slipped your mind or that you didn't want to voice.

The document will be kept by the bedside allowing ease of access.

This is not to replace face to face communication but to be used to augment the communication process.

Date	Comment	Sign


WITHDRAWAL OF TREATMENT – ALGORITHM
Decision discussed with medical / nursing team and speciality team
Complete DD1
NO
DO NOT CONTINUE
Treatment withdrawal decision discussed with patient / family / significant other.
Commence Communication Log (DD5)
Discuss preferred place of care.
Ward / Hospice / Home
(Sending Home to die Guidelines)
Decision to withdraw treatment agreed (DD2)
NO
Discuss with senior medical/nursing staff.
Give time and support.
Decision documented in nursing/medical notes.
Care / decision making must be consistent
Refer to Specialist Nurse for Organ
Organ / tissue donation considered and documented
NO
FAMILY PREPARED & PRESENT
Consider contacting chaplain
Implement changes in care
Assess patient's appearance. Are they comfortable (DD3)
Repeat assessment and document (DD3) at least 4hourly and deliver interventions if required
See flow charts for guidance
Repeat full MDT Assessment (DD4) if:
It is 24 hours since last assessment
There is an improvement in condition
Concerns have been raise about plan of care
Ensure family significant other remain fully informed and are able to stay with the patient as long as possible and their needs and wishes considered.

HINDU

BELIEFS

Hindus believe in reincarnation. When a person dies their soul merely moves from one body to the next on its path to reach Nirvana (Heaven). So, while it is a sad time when someone dies, it is also a time of celebration.

PREPARING

Family and a priest may come to pray with the dying person, sing holy songs and read holy texts. The priest may perform last rites.

AT THE TIME

Family will pray around the body soon after death. People try to avoid touching the body as it is considered unclean.

FUNERAL

The deceased will be bathed and dressed in white traditional Indian clothing. If a woman dies before her husband she will be dressed in red. The procession might pass by places that were important to the deceased. Prayers are said at the entrance to the crematorium. The body is decorated with sandalwood and flowers. Someone will read from the scriptures. The head mourner is usually a male or the eldest son and he will pray for the body's soul.

BURIAL

Hindus are cremated as they believe burning the body releases the spirit. The flames represent Brahma (the creator).

AFTER

A priest will purify the family's home with spices and incense. A mourning period begins during which friends and relatives can visit the family and offer their sympathies. After the funeral mourners must wash and change their clothing before entering the house.

One year later Shradh occurs. This is either a one-off event or may become an annual event. Shradh is when food is given to the poor in memory of the deceased. Shradh lasts one month and a priest will say prayers for the deceased; during this time the family will not buy any new clothes or go to any parties.

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

hospice UK

Sue Ryder

What to expect when someone important to you is dying

A guide for carers, families and friends of dying people

In conclusion

Most dea cal or critical care beds

fe Care Audit 2016

Provide g eccn.org.uk

In an age of technology – don't forget the PERSON

You matter because you are you, you matter to the last moment of your life and we will do all we can to let you die peacefully.

Thank you for listening

Contact: julie.platten@nth.nhs.uk

Acknowledgments to **NoECCN End of Life Working Group** for their help

Lesley Durham (NoECCN) , Anita McGuire (NuTH), Barbara Jameson (CCDFT), Catherine Smith (UHNT), Joanne Wilkinson (QE), Julia Dodsworth (CDDFT), Pauline Carey (CHS) Sue Smith (UHNT),

Sue Soulsby (CDDFT), Tracey Ryder (JCUH)

References

G Masterton & S Baudouin. ***Guidelines for the Provision of Intensive Care Services***. London: Faculty of Intensive Care Medicine & Intensive Care Society 2015**.**

Leadership Alliance for the Care of the Dying People. ***One Chance to Get it Right: Annex C: Priorities of Care of the Dying Person.*** London: Department of Health, 2013.

Royal College of Physicians. ***End of Life Care Audit – Dying in Hospital.*** London:RCP,2016.