End of life care in Critical Care

A summary of key nursing care priorities and information on the bereavement follow-up service

- No one expects to or wishes to die in critical care – it can be a particularly distressing experience for all involved
- Unfortunately, around 15-20% of UK intensive care admissions die in hospital
- The key is in effective decision making prior to admission and establishing whether the benefits of treatment outweigh the risks
- There should be a duty to have open and honest discussions about difficult decisions with the intention of increasing public awareness about the burdens as well as the benefits of critical care
- The focus of care should enable patients, their families and critical care teams to work through shared-decision making processes
- There is now more emphasis on people developing individualised end of life care pathways prior to ever becoming acutely unwell, via their GP and having this clearly documented on Trak

Collaborative evidence gathering, listening, reasoning and implementing appropriate, individualised care plans

What we know, however...

- Critical care survival particularly when associated with emergency and prolonged admission (>48-72 hours) carries significant physical and psychological burdens impacting on future quality of life (Griffiths et al., 2013)
- More than 80% of critical care patients lack capacity to make important decisions about their care and management at a time when consideration is being given to witholding or withdrawing life-sustaining treatments (Sprung et al., 2018)
- Only 13% of patients dying on critical care have made any pre-emptive statement (Sprung et al., 2018)
- 24% of critical care survivors are re-admitted to hospital within 90 days of discharge. The reason being is usually chronic health status prior to original critical care admission

- End of life care is a necessary core skill for critical care nurses. Such care should include:
  - Symptom assessment and management (pain, nausea, pyrexia, anxiety, delirium, skin care, thirst & hunger
  - Enabling patients, and those close to them to achieve a sense of control
  - Minimising distress
  - Relieving physical and psychological burdens
  - Ensuring patients and family members are supported through the course of the dying process
  - Meeting spiritual and religious needs
  - Understanding legal and ethical principles related to withdrawal and witholding treatments

Health care professionals within critical care have a duty to recognise when patients are close to death, and to change the focus of care towards comfort at the end of life

As a healthcare professional it is helpful to think about what would be important to you if you were a patient receiving end of life care, or what experiences you would want those close to you to have?

Kindness and compassion would be high up on your list!

An empathetic approach can feel like a lifeline and will be remembered by families for a long time afterwards

Excellent communication is paramount

Family members are often distressed by the events that are unfolding and often find it difficult to absorb information, therefore regular updates and reassurance is required

Family members have to live the rest of their lives with the decisions that are made on behalf of the patient. These decisions must be high quality, transparent, evidence based and in the patients best interests, taking into account their values and wishes

This is all a very big responsibility, be sure to ask for support from your Nurse in Charge

Care at the End of Life

A practical approach

Involving families/patients

- If possible remember to enquire the beliefs and values of your patient and whether there is any form of advance statement
- Explain every element of care you are about to provide to your patient, even if they appear unconscious
- Explain care to families who might not understand certain processes

Symptom monitoring and review

- Assessing symptoms (pain/nausea/anxiety), and acting to stop them is a cornerstone of supportive care. This can be challenging, and non verbal assessments may be necessary
- A multi-disciplinary approach is invaluable and required to assess medication options and routes (sub-cut, IV)

https://bnf.nice.org.uk/guidance/prescribing-in-palliative-care.html

Pain and Pain Control

- Pain is common in critical care patients near the end of their life
- Be sure to continue to regularly assess
- Where patients are unable to communicate, assessment relies on observing physiological and behavioural manifestations of pain via this tool: Critical Care Pain Observation Tool
- Most commonly we use an IV morphine infusion with IV paracetamol
- Opiods cause constipation, so be sure to consider this factor and ask for laxitives should you require them

Anxiety/Distress/Agitation/Delirium

- These symptoms are very common
- If communication is possible, calm reassurance, information, distraction and the presence of family can assist in minimising symptoms
- For patients who cannot communicate, administration of sedative medication can be considered after reversible causes have been excluded (pain)
- Most commonly we use IV Midazolam
- Agitation and delirium are common and is not usually effectively managed by sedation alone, and the use of anti-psychotic medications may have to be considered: National Delirium Guidance

Dyspnoea and Respiratory Secreations

- Breathlessness can compound anxiety (Schmidt et al., 2014)
- Opioids can reduce the sensation of breathlessness (Devlin et al., 2018; Puntillo et al., 2014)
- Non-intubated patients have a build up of respiratory secreations causing noisy breathing. Suctioning can cause distress so there is a role for the use of hyoscine to minimise secreation production

Skin and Eye Care

- Skin is at high risk of breakdown from immobility, hypermetabolism, infection, hypoperfusion, steroids, vasoconstricter medication (Chaboyer et al., 2018)
- Skin care focuses on infection prevention and control, prevention of pressure sores and regular repositioning
- Regular eye care with water and liberal use of ointment lubricants to enhance comfort is important

Thirst, Mouth Care, Nausea, Hunger and Withdrawal of Hydration and Nutrition

- Thirst (difficult to distinguish from dry mouth) has been rated as one of the most distressing and intense symptoms experienced by patients at high risk of dying (Oechsle et al., 2014; Puntillo et al., 2010)
- Simple treatments include frequent provision of ice, wet oral swabs and lip moisturisers. Saliva substitutes and gentle tooth brushing can also help
- The need for nutrition needs to be considered case by case basis

Extubation and Ventilatory Withdrawal

- This is consultant led but can be a particularly daunting experience for the bed space nurse. Guidance and support should be sought from a more senior and experienced nurse
- It is completely individualised decision, depending on what is considered the most appropriate and comfortable action for the patient
- If the patient has no voluntary breathing ability (brain stem death), the patient will likely die extremely quickly
- Before extubation is considered it is highly advisable to prepare the family first and have them available to sit with the patient as soon as possible
- It can be common that the patient develops an obstructive, noisy breathing pattern. This can be minimised by placing the patient on their side to help open their airways
- Sometimes the decision will be made to keep the patients ET tube in place but to put a swedish nose on to help maintain comfort

Dealing with vasoactive medications

- Stopping vasoactive medications (Noradrenaline) is not known to cause discomfort but should be explained and planned for as death can often follow rapidly
- Deactivation of implantable cardiac defibrillators will prevent a shock from being delivered

Environment

- Please minimise the bedspace as much as possible, in order to help “humanise” the surroundings
- Remove unnecessary technology and place screens/alarms on privacy
- Consider things like: subtle lighting, own clothes/bedding, own music, smells and photographs (Pattison et al., 2013)
- Please offer free parking to family members and consider whether they require accommodation?

Discharge from Critical Care to other areas

- This may be considered if the patient appears unlikely to die within 24-48 hours of commencing end of life care
- This does require significant planning factoring in the transfer of IV medication pumps to suitable alternative pumps
- A palliative care referral should be made so that the team can link in with the patient once they are on the ward

- Please consider this early on during the patients stay in critical care
- Information is available here: NHS Spiritual Care
- There is a spiritual and cultural box located in reception containing most things you might need including lots more information

Spiritual Needs and Cultural Sensitivity at End of Life

Last Offices and Documentation

- Guidance on how to provide last offices is provided on the intranet
- Please complete all relevant paper documentation. The packs are kept in the reception, to include:
  - Guideline for the provision of End of Life Care
  - Bereavement Checklist
  - Indemnity Form
  - Death Certification
  - Infection Form
  - Deceased Identification cards

Support for Staff

- Support is here for you at any time! Please always link in with your Band 6 or Band 7 if you are struggling with anything or if you have had more than one withdrawal in a row. We would never expect anyone to be able to handle more than that in a short period of time
- It is important that you do reflect and take time out during your shift if you are finding caring for your patient or family particularly stressful
- You can access psychological support at any time by contacting the staff psychologist for a private chat or it might simply be enough to off load to your team members?

Bereavement Care

- The incidence of complicated grief is higher in the families of critical care patients (Kentish-Barnes et al., 2015)
- Discretion and sensitivity are required, in order to guide the family through an understanding of death in terms of both individual and cultural perspectives
- Bereavement care services are important to signpost at this time with written information being provided for families (Faculty of Intensive Care Medicine, 2019; Intensive Care Society, 1998)
- Bereavement tools and mementoes (locks of hair, handprints) can help those close to the patient

As some of you may all already know, this unit runs a bereavement follow-up service which is primarily nurse led. It has been fully up and running for the past 5 years

As a group of nurses we are here to support one another and provide information on all things relating to end of life care – please have a look at what we do and let us know if there is anything you think we could improve on or help you with.

The bereavement follow-up service now offers relatives the opportunity to liaise with healthcare professionals involved and discuss unanswered questions enabling clarification of the facts surrounding the death of their loved one. This often involves a joint approach with consultant medical staff

We send a sympathy card inviting families or the closest NOK to get in touch should they so desire

We have a dedicated answer phone and email address that we follow up

Often families get in touch just to say thank you for the care we provide

Occasionally, there are some family members who during sudden death scenarios in ICU forget the pertinent details that were explained to them at the time and need this explained again in more simpler terms. Or for reassurance that they weren't to blame

We can link in with the chaplaincy, NHS Lothian's Bereavement Project or many of that other bereavement charities that exist

Our goals are to:

• To allow a more consistent approach to bereavement care

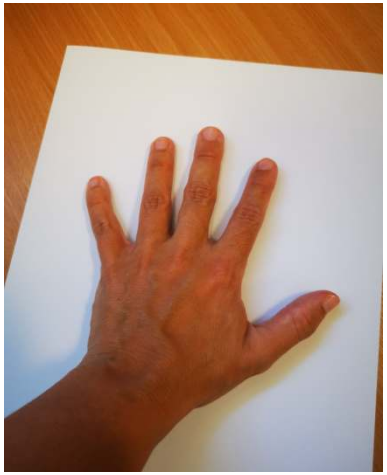
• To share our specialist knowledge of critical illness which will hopefully assist understanding of the end of life care we provide, thereby facilitating the bereavement process

•We hope to evaluate what we do – to gain a better understanding of what relatives require when they have experienced a bereavement within our unit

•To do what we can do to reduce the number of complaints (the 2007 Healthcare Commission highlighted that 54% of NHS complaints were bereavement related)

•And to comply with the Scottish Patient Safety Programme whereby one of the primary drivers is to "integrate patient and family into care so they receive the care they want by promoting open communication among team and family"

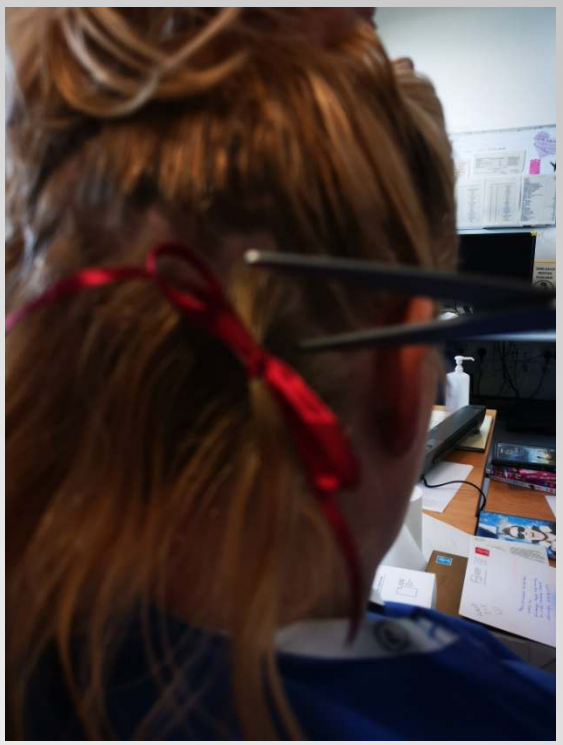
- Gather what you need
- x 1 hand print towlette = 6 handprints
- Cover hand well and position in centre of special activated paper and press firmly down then left carefully to reveal



How to guide, on hand prints

Gather small section of hair at back of patients head and tie a bow with selected coloured ribbon:

Once bow is tied, cut above bow and place neatly in to organza bag:



How to guide, on hairlocks

The Thistle is a discreet sign to indicate to everyone working in the clinical area that patient care has progressed to end of life care.

Please, if you see this sign, can you respect the patients dignity and privacy, quieten down any personal or professional discussions as a mark of respect.

Also look out and care for your colleagues whilst caring for a dying patient. Work together as a team and support one another.

The Thistle Picture

The cupboard in recption and the new rainbow boxes with end of life care mementoes

NOK address

- Please, let the family know about the bereavement follow-up service verbally
- Please, please gather the NOK/family members address and pop this onto Ward Watcher so that we can send details out to them

- Chaboyer, W.P., Thalib, L., Harbeck, E.L., Coyer, F.M., Blot, S., Bull, C.F., Lin, F.F. (2018) Incidence and Prevelance of Pressure Injuries in Adult Intensive Care Patients: A Systematic Review and Meta-analysis. Critical Care Medicine, 46(11), e1074-e1081
- Devlin, J.W., Skrobik, Y., Gelinas, C., Needham, D.M., Slooter, A.J.C., Pandharipande, P.P., Alhazzani, W. (2018). Clinical Practice Guidelines for the Prevention and Management of Pain, Agitation/Sedation, Delirium, Immobility, and Sleep Disruption in Adult Patients in the ICU. Crit Care Med, 46(9), e825-e873.
- Faculty of Intensive Care Medicine. (2019). Guidelines for the Provision of Intensive Care Services Version 2. Retrieved from London: https://www.ficm.ac.uk/sites/default/files/gpicsv2
- Griffiths, J., Hatch, R.A., Bishop, J., Morgan, K., Jenkinson, C., Cuthbertson, B.H., & Brett, S. (2013). An exploration of social and economic outcome and associated health related quality of life after critical illness in general intensive care unit survivors: a 12 month follow-up study. Crit Care, 17(3), R100.doi:10.1186/cc12745
- Intensive Care Society. (1998). Guidelines for Bereavement Care in Intensive Care Units. Retrieved from https://www.ics.ac.uk/AsiCommon/Controls/BSA/Downloader.aspx?iDocumentStorageKey
- Oechsle, K., Wais, M.C., Vehling, S., Bokemeyer, C., & Mehnert, A. (2014). Relationship between symptom burden, distress, and sense of dignity in terminally ill cancer patients. J Pain Symptom Manage, 48(3), 313-321
- Pattison, N., Carr, S.M., Turnock, C., & Dolan, S. (2013). Viewing in slow motion: patients, families, nurses and doctors perspectives on end of life care in critical care. J Clin Nurse, 22(9-10), 1442-1454
- Puntillo, K., Arai, S.R., Cooper, B.A., Stotts, N.A., & Nelson, J.E. (2014). A randomized clinical trial of an intervention to relieve thirst and dry mouth in intensive care unit patients. Intensive Care Medicine, 40(9), 1295-1302
- Puntillo, K.A., Arai S., Cohen, N.H., Gropper, M.A., Neuhaus, J., Paul, S.M., & Miaskowski, C. (2010). Symptoms experienced by intensive care unit patients at high risk of dying. Critical Care Medicine, 38(11), 2155-2160
- Schmidt, M., Banzett, R.B., Raux, M., Morelot-Panzini, C., Dangers, L., Similowski, T., & Demoule, A. (2014). Unrecognised suffering in the ICU: addressing dyspnea in mechanically ventilated patients. Intensive Care Medicine, 40(1), 1-10.
- Sprung, C.L., Somerville, M.A., Radbruch, L., Collet, N.S., Duttge, G., Piva, J.P., Ely, E.W. (2018). Pysician-Assisted Suicide and Euthanasia: Emerging Issues From a Global Perspective. J Palliate Care, 33(4), 197-203.