**Ethical Framework for Nutrition and Hydration towards the End of Life: Good Practice for Nursing Care**

## 1. Introduction:

Supporting those who are approaching the end of their lives, to maintain nutrition and hydration that is appropriate to their individual needs and preferences, is a vital component of palliative and end of life nursing care. However, such issues are often complex and involve ethical considerations. Decision making requires impeccable holistic assessment from the multidisciplinary team, led by a senior experienced clinician, together with the use of objective ethical principles and reasoning.

This toolkit provides a simple framework for nurses and other members of the multidisciplinary team to use in clinical practice, in order to support ethical reasoning that is required as part of the assessment and decision making process, when caring for individuals who are approaching the end of their lives to maintain appropriate nutrition and hydration and receive maximum benefit from treatment and care.

## 2. Ethical Toolkit:

### 2.1. Assess and establish the relevant clinical facts of the case:

2.1.1. What are the relevant features of the patient's clinical condition?
2.1.2. Is the patient expected to die (or not) in the next few days or hours?
2.1.3. What are the goals and priorities for care?
2.1.4. What are the possible options concerning nutrition?
2.1.5. What are the possible options concerning hydration?
2.1.6. What are the expected benefits, burdens and risks of the possible options?

### 2.2. Assess and establish the wishes of the patient and those important to them:

2.2.1. Does the patient have capacity?

For further information, see links below for local mental capacity legislation across the UK:

**England & Wales:**

- Legislation.gov.uk. Mental Capacity Act 2005. Persons who lack capacity. *http://www.legislation.gov.uk/ukpga/2005/9/part/1*

**Scotland:**

- Adults with Incapacity Act 2000 *http://www.legislation.gov.uk/asp/2000/4/section/1*

**Northern Ireland:**

- Department of Health, Social Care & Public Safety and Department of Justice. Draft Mental Capacity Bill (2015) *http://www.dhsspsni.gov.uk/showconsultations?txtid=68523*
- Department of Health, Social Care & Public Safety (Northern Ireland). Good Practice in Consent, Consent for Examination, Treatment or Care

http://www.dhsspsni.gov.uk/index/phealth/professional/professional_good_practice_guidelines/public_health_consent.htm

- The Mental Health NI Order (1986)
  http://www.nidirect.gov.uk/the-mental-health-act

If Yes:

2.2.1.a. Does the patient have an Advance Care Plan?

For further information, see links below for local advance care planning information across the UK:

**England:**

- Gold Standards Framework. Advance Care Planning
  http://www.goldstandardsframework.org.uk/advance-care-planning
- End of Life Care for Adults. Advance Care Planning: A Guide for Health and Social Care Staff
  http://www.bgs.org.uk/pdf_cms/reference/advance_Care_Planning.pdf
- National End of Life Care Programme. The difference between general care planning and decisions made in advance. 2012.
  http://socialwelfare.bl.uk/subject-areas/services-activity/health-services/nhsnationalendoflifecareprogramme/139500EoLC_Care_Planning_WEB.pdf
- Dying Matters Website.
  http://dyingmatters.org/

**Wales:**

- Palliative Care in Wales. Advance Care Planning (wIPADS)
  http://wales.pallcare.info/index.php?p=sections&sid=68
- Welsh Government. Together for Health: Delivering End of Life Care (2013)
  http://gov.wales/docs/dhss/publications/130416careen.pdf
- Dying Matters Website.
  http://dyingmatters.org/

**Scotland:**

- Scottish Government 2010: Anticipatory Care Planning Frequently Asked Questions
  http://www.scotland.gov.uk/Resource/Doc/309277/0097422.pdf

**Northern Ireland:**

- Strategy for Palliative & End of Life Care
  http://www.dhsspsni.gov.uk/index/publications/publications-search.htm?pubtitle=Living%20Matters%20dying%20Matters&class=All

**UK Wide:**

- Macmillan Cancer Support: Advance Care Planning
  http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Advancedcancer/Advancecareplanning/Advancecareplanning.aspx

2.2.1.b. What are the patient's preferences and priorities for their care, including their cultural and religious views?

2.2.1.c. What are the patient's actual and preferred places of care?

2.2.1.d. What information or other support does the patient need to help them with decision making?

If No:

2.2.1.e. Are there any possible reversible causes that can be treated to enable the patient to have capacity?

2.2.1.f. Does the patient have a Lasting Power of Attorney (LPA) or Independent Mental Capacity Advocate (IMCA)?

For further information, see links below for local mental capacity legislation across the UK:

**England & Wales:**

- Legislation.gov.uk. Mental Capacity Act 2005. Lasting Powers of Attorney. *http://www.legislation.gov.uk/ukpga/2005/9/part/1/crossheading/lasting-powers-of-attorney*
- Legislation.gov.uk. Mental Capacity Act 2005. Independent Mental Capacity Advocate Service. *http://www.legislation.gov.uk/ukpga/2005/9/part/1/crossheading/independent-mental-capacity-advocate-service*

**Scotland:**

- Adults with Incapacity (Scotland) Act (2000): Continuing Powers of Attorney and Welfare Powers of Attorney. *http://www.legislation.gov.uk/asp/2000/4/part/2*

**Northern Ireland:**

- Department of Health, Social Care & Public Safety and Department of Justice. Draft Mental Capacity Bill (2015) *http://www.dhsspsni.gov.uk/showconsultations?txtid=68523*
- Department of Health, Social Care & Public Safety (Northern Ireland). Good Practice in Consent, Consent for Examination, Treatment or Care *http://www.dhsspsni.gov.uk/index/phealth/professional/professional_good_practice_guidelines/public_health_consent.htm*
- The Mental Health NI Order (1986) *http://www.nidirect.gov.uk/the-mental-health-act*

2.2.2. Has the patient previously made an Advance Decision to Refuse Treatment (ADRT)?

For further information, see links below for local mental capacity legislation across the UK:

**England & Wales:**

- Legislation.gov.uk. Mental Capacity Act 2005. Independent Mental Capacity Advocate Service. *http://www.legislation.gov.uk/ukpga/2005/9/part/1/crossheading/advance-decisions-to-refuse-treatment*
- National End of Life Care Programme. 2012. The difference between general care planning and decisions made in advance.

http://socialwelfare.bl.uk/subject-areas/services-activity/health-services/nhsnationalendoflifecareprogramme/139500EoLC_Care_Planning_WEB.pdf

**Scotland:**

- Scottish Executive. 2005. The New Mental Health Act: A Guide to Advance Statements http://www.scotland.gov.uk/Resource/Doc/26350/0012826.pdf

**Northern Ireland:**

- Department of Health, Social Care & Public Safety and Department of Justice. Draft Mental Capacity Bill (2015) http://www.dhsspsni.gov.uk/showconsultations?txtid=68523
- Department of Health, Social Care & Public Safety (Northern Ireland). Good Practice in Consent, Consent for Examination, Treatment or Care http://www.dhsspsni.gov.uk/index/phealth/professional/professional_good_practice_guidelines/public_health_consent.htm
- The Mental Health NI Order (1986) http://www.nidirect.gov.uk/the-mental-health-act

2.2.3. Has the patient previously expressed their preferences and priorities for type and place of care / have they previously made an Advance Care Plan?

Those Important to the Patient:

2.2.4. What are the wishes and preferences of those important to the patient?
2.2.5. What information do those important to the patient need to help them with decision making?

**2.3. Consider and establish the legal perspective:**

*Please Note: Issues regarding the Mental Capacity Act are important here, but not repeated, as addressed in previous section above.*

2.3.1. Are the current / possible options regarded as 'basic care' or 'medical treatment' by law?

For further information, see link below:

- General Medical Council. 2010. Treatment and Care Towards the End of Life: Good Practice for Decision Making http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

**2.4. Assess and establish the ethical features of the case:**

2.4.1. What is our intention of care?
2.4.2. What is our duty of care?
2.4.3. Have we listened to and taken into account the current / previously expressed wishes of the patient and those important to them?
2.4.4. Have we assessed the benefits, burdens and risks of all options and sensitively and effectively communicated these to the patient and those important to them?

## 2.5. Establish the appropriate process to support the decision making:

2.5.1. How quickly does a decision need to be made?
2.5.2. Who from the multidisciplinary team needs to be involved in the decision making?
2.5.3. Who from the multidisciplinary team is the lead clinician who will take overall responsibility for decision making?
2.5.4. Who do you need to ask for advice?
2.5.5. Who do you need to communicate with?
2.5.6. Has the decision making rationale and outcome been documented clearly?
2.5.7. In the event of a disagreement between the multidisciplinary team and the patient and / or those close to the patient, has the lead clinician consulted the appropriate legal framework for resolving the disagreement?

For further information, see link below:

- General Medical Council. 2010. Treatment and Care Towards the End of Life: Good Practice for Decision Making *http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf*