

Serious Medical Treatment Decisions

BEST PRACTICE GUIDANCE FOR IMCA_s

END OF LIFE CARE



Contents

Introduction	3
End of Life Care (EoLC)	3
Background	3
Involvement of IMCAs in End of Life Care	4
Definition of SMT	4
Serious consequences.....	4
Decision maker	5
National End of Life Care Strategy	5
End of Life Care Pathway	6
A Working Definition of End of Life Care	6
Gold Standards Framework (GSF)	8
Stages of GSF.....	8
Liverpool Care Pathway for the Dying Patient (LCP)	9
Preferred Priorities for Care (PPC)	11
Place of death	11
Cultural and religious factors	12
Questions to ask the Decision Maker	13
Questions to ask the person and those that know the person	13
Points to highlight within a report:.....	14
Further guidance & Resources	14
Best Practice Guidance Range	15

Introduction

This guidance was developed by the Action for Advocacy IMCA Support Project and is part of the Serious Medical Treatment (SMT) best practice guidance. It is aimed at IMCAs who are supporting and representing people when best interests decisions about serious medical treatment are being made. Much of the IMCAs role is to ensure that what is important to the person is considered when the decision is being made, to ensure relevant questions are asked on behalf of the person and alternatives suggested where it is believed they would be better suited to the person's wishes and feelings. The guidance aims to support the IMCAs work.

This guidance will cover SMT decisions about End of Life Care. It should be read in conjunction with Action for Advocacy's Instruction and Report Writing guidance where further information about IMCA instruction or writing IMCA reports is needed¹.

End of Life Care (EoLC)

There is a great deal of work that has been done within the field of End of Life Care, covered considerably in the NHS National End of Life Care Programme (NEoLCP)². Therefore this guidance does not aim to duplicate this but instead provide a snapshot of some of the work that has been carried out and will highlight existing programmes that provide a framework for End of Life Care. The aim is to offer IMCAs an overview so that they are then better equipped to ask the responsible clinician relevant questions, and enable them to determine certain factors of importance in relation to each of these, when decisions about End of Life Care are being made, so that the client they are working with is afforded the best possible representation.

Background

The NEoLCP ran from 2004 – 2007, and was subsequently followed by the Department of Health's End of Life Care Strategy³, which drew on research, evidence and existing experience from hospices, the NHS End of Life Programme, the Gold Standards Framework⁴ (GSF), the Liverpool Care Pathway for the Dying Patient⁵ (LCP), and other practices to ensure that when people reach the end of their

¹ www.actionforadvocacy.org.uk

² <http://www.endoflifecareforadults.nhs.uk/>

³ http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_EoLC_Strategy_exec.pdf

⁴ <http://www.goldstandardsframework.nhs.uk/>

⁵ <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>

life they are treated with dignity and respect and that their wishes are at the heart of care planning.

Involvement of IMCAs in End of Life Care

Many IMCAs will be involved in End of Life Care and the decision making process that sits alongside this within their work either because of instruction for serious medical treatment, proposals to change someone's place of accommodation because there are concerns about their needs and whether these can be met within their current environment; care reviews or safeguarding. It is therefore important to be familiar with the relevant framework that informs the care of someone at the end of their life as well as what the different stages of care may be. It is hoped that the information laid out within this guidance can support the often time limited work that IMCAs carry out.

Definition of SMT

Regulations for England and Wales define serious medical treatment⁶. It involves:

- giving new treatment
- stopping treatment that has already started, or
- withholding treatment that could be offered

In circumstances where:

- if a single treatment is proposed there is a fine balance between the likely benefits and the burdens to the patient
- a decision between choice of treatments is finely balanced, or
- what is proposed is likely to have serious consequences for the patient

Serious consequences

Serious consequences are those that could have a *serious impact* on the patient either from the treatment itself or due to wider implications such as:

- prolonged pain
- distress
- side effects of the treatment such as reduced immunity

⁶ <http://www.legislation.gov.uk/ukSI/2006/1832/regulation/4/made>

- major consequences such as stopping life sustaining treatment or amputation
- serious impact on a patient's future life choices

A person will have a right to an IMCA if such treatment is being considered on their behalf.

Decision maker

The decision maker is the person within the responsible body who is required to ultimately make the decision. For decisions about serious medical treatment the responsible body is the relevant NHS organisation. The MCA Code of Practice (6.17)⁷ clarifies this further by advising whomever is providing treatment will be the decision maker therefore for different decisions this can be a range of professionals, but for most SMT decisions this is likely to be a medical consultant with specific expertise in the area of decision making e.g. orthopaedics, dentistry, oncology, surgery etc.

National End of Life Care Strategy

The strategy was published in July 2008 and provides a framework aimed at promoting high quality care in England for adults that are approaching the end of their life. According to the strategy, half a million people die in England a year with many of these being over the age of 75. It highlights that whilst most people would prefer to die at home the reality is that most people now die in hospital. 85% of people in the early part of the 20th century died at home, now only 18% of people die at home and many of these are under the age of 65. Those over the age of 65 make up the majority of those that will often die in hospital, hospice or a care home. The majority of deaths in this country are due to chronic illness such as heart disease, stroke, dementia and respiratory diseases which would suggest that most people will be under the care of health or community services.

The strategy reflects that whilst some people may die as they'd wish, many die in pain without respect or dignity and comments that this illustrates how we care for the sick and the vulnerable in this society. It also states that the profile of End of Life

⁷ <http://www.publicguardian.gov.uk/docs/mca-code-practice-0509.pdf>

Care within the NHS has been low, and the quality of care variable. It is therefore hoped that through the implementation of the strategy, these issues can be addressed and change the quality of care that people receive.

End of Life Care Pathway

The EoLCP is a 6-step process, which aims to ensure that there is a quality of care approach when someone is at the end of his or her life. This may mean a person has been given a diagnosis of illness that is known will be terminal. The care pathway enables the person to prepare in advance how they would like their care to be specifically delivered. It also allows for the professionals involved in the delivery of that care to plan for what the person would like to happen as well ways to support the family, friends and carers of the person both before death and through subsequent bereavement.

A Working Definition of End of Life Care

End of life care is care that:

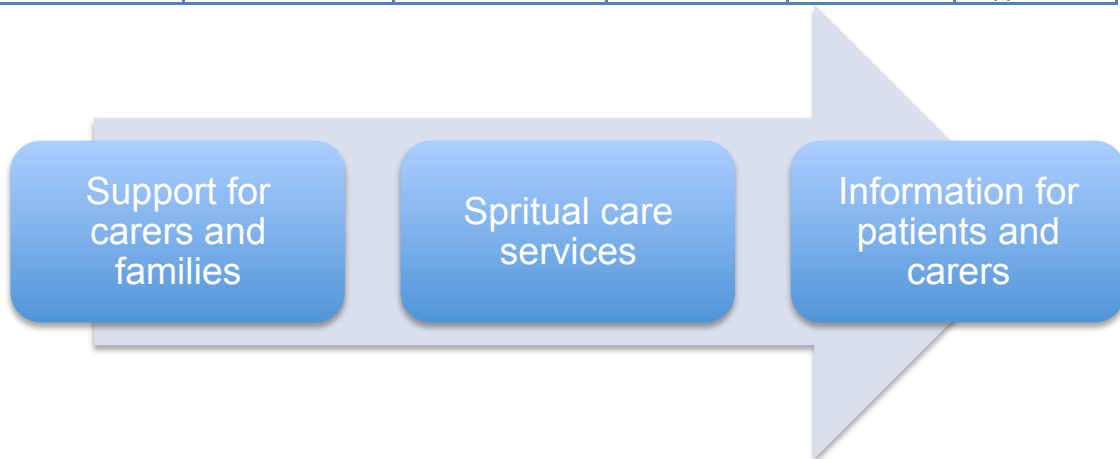
Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

Source: National Council for Palliative Care 2006

Where IMCAs become aware that a person they are working with is either to be placed on an End of Life Pathway or already has a care plan in place the table below details the process and what needs to be considered, discussed and/or planned for by the professionals responsible for that person's care, for example if someone is at step 5 the IMCA can focus their questions to decision makers about how the person's wishes can be met.

The following pathway starts at step 1 although some patients may start the pathway at step 5, much of this will depend on the nature as well as diagnosis of the illness. For example a person may be given a diagnosis of dementia early into the onset of the illness and they will be afforded the time and opportunity to have discussions and make plans. Others however may become acutely unwell suddenly and their care plan may only be able to focus on the last few days of their life.

Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Discussions as the end of life approaches	Assessment, care planning and review	Coordination of care for individual patients	Delivery of high quality services in different settings	Care in the last days of life	Care after death
Open, honest communication - Identifying triggers for discussion	Agreed care plan and regular review of needs and preferences - Assessing needs of carers	Strategic coordination • Coordination of individual patient care • Rapid response services	High quality care provision in all settings - Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels - Ambulance services	Identification of the dying phase - Review of needs and preferences for place of death - Support for both patient and carer - Recognition of wishes regarding resuscitation and organ donation	Recognition that end of life care does not stop at the point of death. - Timely verification and certification of death or referral to coroner - Care and support of carer and family, including emotional and practical bereavement support



“It is important to consider the support, care and information that is required by the person’s family and caregivers both during the illness and into bereavement. Similarly, spiritual care and support for both the person and their carers is integral to the end of life care pathway”.

Source: End of Life Care Pathway Strategy 2008

Gold Standards Framework (GSF)

Dr Keri Thomas, a GP who specialised in palliative care, developed the Gold Standards Framework in the year 2000; the aim of the project was to improve palliative care from within primary care. The programme was piloted in Yorkshire in 2001 and subsequently rolled out nationally, it has been endorsed and recommended by numerous organisations including Macmillan Cancer Support, NICE, The Royal College of General Practitioners, The End of Life Care Programme and the Department of Health to name a few.

Stages of GSF

The National GSF Centre⁸ provides training on the framework, the approach, the resources and tools used as well as how these are utilised within different settings – primary care, care homes, acute hospital and other settings. There are 3 stages that all have a number of tools and evidence based resources attached to them:

Identify

The first stage is to identify whether someone is in the last year of life, which would then allow the framework to be put in place. One of the resources attached to this stage is the ‘surprise question’ which asks of those involved in the care of a person if they would be surprised if that person died within the following weeks, months or years. This is only one aspect of identifying whether end of life care needs to be considered the ‘Prognostic Indicator Guidance’ and ‘needs based coding’ also support those delivering the person’s care to fully explore this stage. Details of these resources and assessment tools can be accessed at the National GSF Centre.

Assess

At this stage the person’s needs are assessed including clinical, personal and future needs using advance care planning amongst other tools.

Plan

Finally the plan as to how to align the care with what the person’s wishes are is made and this looks in detail at how to do this including reducing any admission to hospital.

The basis of the framework is to ensure inter-agency care and planning so that all patients regardless of their environment can receive a quality standard of care that

⁸ <http://www.goldstandardsframework.nhs.uk/ContactUs/>

places them at the heart of the process enabling them to both live and die as they would choose.

An understanding of the level of assessing that is involved with the GSF in terms of the necessary tools and resources may not be relevant to the IMCA role but IMCAs may wish to access some further basic training if they are regularly working in care homes or hospitals where the framework is used if it is felt it will support them in their representation of the person.

IMCAs that are involved with someone that has the GSF in place can access that person's care plan, this will contain information as to how the person will be cared for in their last months, weeks and days and offer a valuable insight into a person's wishes. Where those wishes are not known, for example a person is admitted to a care home or hospital and is unable to express their feelings and beliefs about the subject this may mean that the IMCA asks more questions on the person's behalf rather than articulating their wishes. A suggestion as to what some of these may be is provided later in this guidance.

Liverpool Care Pathway for the Dying Patient (LCP)

The Liverpool Care Pathway is a framework developed by the Marie Curie Palliative Care Institute Liverpool (MCPCIL)⁹ which was established in 2004 and is a collaboration between the Marie Curie Cancer Care, the University of Liverpool and the Royal Liverpool and Broadgreen University Hospitals NHS Trust and is led by John Ellershaw, Professor of Palliative Medicine at the University of Liverpool, Medical Director at the Marie Curie Hospice Liverpool and Clinical Director of the Specialist Palliative Care Directorate at the Royal Liverpool and Broadgreen University Hospitals NHS Trust (RLBUHT).

The institute describes itself as a "leading organisation in the field of palliative care, with a specific focus on end of life care and care of the dying". The institute's major focus is the LCP. The framework is to deliver an integrated care pathway that focuses on bedside provision of quality care for the dying patient in their last hours and days. It is a model of best practice care that is recommended by the Cancer Services and Collaboration project and the National End of Life Care Programme

⁹ <http://www.mcpcil.org.uk/about-us/index.htm>

(2004 – 2007), NICE and the Department of Health's End of Life Care Strategy to name a few.

The LCP is used when the multidisciplinary team in the relevant care setting has agreed the patient is dying and therefore their care is specifically focused to be about their needs in their last days and hours of life. When a patient is placed on the pathway they are assessed on a regular basis and a review is carried out every 3 days to ensure that it is appropriate for them to remain on the pathway; for example their health may unexpectedly improve and therefore their care needs will change.

The LCP encompasses the needs of the patient as well as those closest to the patient and ensures that religious, spiritual and communication needs are considered as well as ensuring there is appropriate level of information provided about what family or carers can expect (this will include the patient where possible).

The LCP Pocket Guide¹⁰ highlights

“The current plans of care need to be reviewed and inappropriate interventions stopped when the burden of an intervention or treatment outweighs the benefits. There are occasions when a patient who is thought to be dying lives longer than expected and vice versa. A second opinion of the support of a palliative care team may be required. Good comprehensive clear communication is pivotal and all decisions leading to a change in care delivery should be communicated to the patient where appropriate and to the relative and carer. The views of all concerned must be listened to and documented”.

The role of the IMCA is to ensure there is a safeguard for someone who does not have family or friends so that they can be represented when life-changing decisions are taking place. Clearly the last days or hours of someone's life are crucial in terms of the quality of care that is provided. IMCAs may be able to impart valuable information on behalf of the patient, for example if they have known them prior to the pathway commencing and are aware of their wishes including cultural or spiritual needs. Patients, whilst very ill may be able to understand some of what is happening

¹⁰ <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/pdfs/LCP%20Pocket%20Guide%20printable%20pdf.pdf>

around them and IMCAs, may be able to provide support at this time. It should also be highlighted that IMCAs may have worked closely with the patient and therefore may themselves require support from their organisation when they are faced with end of life situations.

Preferred Priorities for Care (PPC)

PPC¹¹ was an initiative developed in Lancashire and South Cumbria as an advance care plan and is endorsed by the NHS End of Life Care Programme. Initially designed to facilitate a person's choice in terms of their end of life care it is an explicit recording of their wishes, values and factors they would want to be considered. The aim is for it to be used should the time come when the person is no longer able to express these wishes themselves. It also allows for a person to state who their Attorney (under LPA) is if they have one or who they would wish to be contacted about their care if they don't.

IMCAs may come across PPCs within their work where someone has been able to complete an advanced care plan. Or the PPC can also be used as a tool to record who and what is important to someone, which IMCAs can ask to access in order to support their work in representing the person.

Place of death

Where a person ends their last days is an individual and very personal decision and belief. Even where a person lacks capacity they can often still indicate a preference. There are various factors that can influence this such as wanting a specialised environment for example a hospital or hospice where they know they will be looked after at all times and until the end. Others may not wish to die alone but their circumstances may mean this is the reality. Other factors include not wanting to be a burden on family or friends or alternatively wanting to be surrounded by family and friends, indeed this may be part of their culture albeit difficult to then enact if someone no longer has contact with their family. Evidence suggests that most people want to die at home in an environment they are familiar with, possibly with their pets, neighbours or friends near them. The End of Life Strategy was developed to ensure that a person's wishes are kept at the heart of the decision when end of life planning takes place in line with the Mental Capacity Act 2005. Whilst professionals

¹¹ <http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare>

involved in these decisions may feel that an alternative environment i.e. 24hour care would suit their needs more, the best interests checklist still needs to be considered and the person's wishes deemed as valuable and important in that decision making process.

It should be acknowledged that best interest decisions about where a person dies may not be easy when their needs are not in line with their wishes. However the role of the IMCA is to ensure questions are asked and representation provided on behalf of the person. Some suggestions of possible questions to ask are offered later in the guidance.

Cultural and religious factors

A patient's religious or cultural beliefs may impact on the decision making process of End of Life Care and so it is important to determine as far as possible whether they practiced any particular faith as well as being able to ascertain cultural beliefs. Consideration should be given to the fact that whilst someone may have been born into a particular faith they may no longer practice it, equally they may have changed faiths as an adult or have been devout to their religion all their lives and often neighbours or friends (or care home staff) can offer an insight into this.

Culture can sometimes be narrowly viewed as only being connected to religion. Similarly, it is sometimes only taken into consideration when a person's culture is different to the prevailing culture of the society they currently live in but it is inherent in all of us and as such needs to be understood in order to be able to represent the person.

However being able to research differing cultures, religions, and their belief systems may be difficult if someone is unable to express or explain this themselves but it is important to ask questions on behalf of the person about these factors and equally important not to assume.

It may not be possible to find out much detail about a person's cultural or religious wishes with respect to end of life particularly from a person that is at the end stages of their life as they may be too unwell to communicate. Factors such as limited communication, understanding of the concept of death by the person and time constraints within the decision making process or the IMCAs involvement may too

impact on gathering this information however it should still be considered as part of the decision making process and by IMCAs as the person's representative.

Questions to ask the Decision Maker

Q: Is there a framework in place to be aware of in terms of care planning e.g. End of Life Care Plan?

Q: What step of the End of Life Pathway is the client at?

Q: Is funding available e.g. Continuing Healthcare (CHC) or been considered in order to enable their wishes to be carried out i.e. if a person needs 24hour care yet have only days, weeks or months to live, can the provision of this be carried out within their own home?

Q: Does the person have pets that need to be considered in terms of re-homing?

Q: If family or friends are involved but have been deemed inappropriate to consult with are the wishes of the person known with respect to their involvement? Where family or friends have been deemed inappropriate to consult, the relationship the person had with them is still pertinent.

Q: Has the person's faith, beliefs or culture been considered in terms of their care plan?

Q: Has the least restrictive option been explored fully for example if the person wishes to die either at home – or in hospital, can this occur?

Q: If the person is in pain, how is pain controlled?

Q: Is there a DNAR order in place?

Questions to ask the person and those that know the person

Q: Has the person expressed their preference, wishes, views or feelings either in the past or now as to where they would prefer to die?

Q: Has the person expressed a preference about being looked after by their family? Where family has been deemed inappropriate to consult with albeit still have a relationship with the person this may need to be considered.

Q: Is there knowledge of how the person reacts to medical intervention or hospital admission? Is this part of their care plan for example providing care at home to ensure the person is not distressed in their last days by admission to hospital.

Q: Does the person practice any religion or does their culture stipulate any specific process in terms of how they should be cared for before and/or after death?

Q: Does the person have an advanced care plan?

Q: Is there any information as to where the person would want to be buried or how their funeral would be?

Points to highlight within a report:

- The physical, emotional and psychological impact on the person if their wishes about where they die are not met
- Expressed preferences of the person about End of Life Care
- Views of their family or friends but also their perception of what decision the person would have made if they could
- The least restrictive option
- DOLS consideration
- Relevant legal guidance for example the Human Rights Act or recent case law

Further guidance & resources

End of Life Care Strategy

www.endoflifecareforadults.nhs.uk

National End of Life Care Intelligence Network

www.endoflifecare-intelligence.org.uk

Marie Curie Palliative Care Institute Liverpool

www.mcpcil.org.uk

Marie Curie Delivering Choice Programme

www.deliveringchoiceprogramme.org.uk

Gold Standards Framework

www.goldstandardsframework.nhs.uk

The National Council for Palliative Care

www.ncpc.org.uk

Best practice guidance range

The IMCA Support Project has produced a range of guidance on the involvement of IMCAs in SMT decisions that can be accessed on the Action for Advocacy website under IMCA Support Project, articles and resources.

The involvement of Independent Mental Capacity Advocates in Serious Medical Treatment Decisions

Best Practice Guidance for Healthcare Professionals and IMCAs. Includes case examples, example policies and useful forms.

Serious Medical Treatment - Specific Decision Guidance for IMCAs

The guides cover some common SMT decisions IMCAs may be involved in.

Do Not Attempt Resuscitation (DNAR)

PEG Feeds

Chemotherapy

End of Life Care

Dentistry

ECT Factsheet

Serious Medical Treatment Checklist (for the involvement of IMCAs)

A useful A4 chart, which gives information aimed at health professionals about when to instruct IMCA.

IMCA involvement in SMT decisions leaflet

A leaflet aimed at healthcare professionals which gives information on the IMCA role and when and how to instruct IMCA.

www.actionforadvocacy.org.uk

Action for Advocacy

Registered as a company in England and Wales No 4942158 Charity Number
1103575 Registered Office:

The Oasis Centre
75 Westminster Bridge Road
London
SE1 7HS

Tel: 0207 9214395
Fax: 0207 9214201

www.actionforadvocacy.org.uk

The IMCA Support Project is funded by The Department of Health

© Action for Advocacy 2011