Serious Medical Treatment Decisions

BEST PRACTICE GUIDANCE FOR IMCAs

CARDIOPULMONARY RESUSCITATION and decisions about DNAR

action for advocacy

IMCA Support Project

Contents

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 Cardiopulmonary Resuscitation (CPR) where the person lacks capacity to give or withhold consent to the treatment. It should be read in conjunction with Action for Advocacy's Instruction and Report Writing guidance for IMCAs where further clarity is needed[1].

Definition of SMT

Regulations for England and Wales define serious medical treatment[2]. 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

[1] www.actionforadvocacy.org.uk
[2] 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)[3] 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. orthopedics, dentistry, oncology, surgery etc.

Cardiopulmonary Resuscitation

This guidance will cover Cardiopulmonary Resuscitation (CPR), more specifically where a Do Not Attempt Resuscitation order (DNAR) is put in place. Cardiopulmonary Resuscitation is an emergency procedure that is performed when a person has gone into cardiac arrest.

Cardiac Arrest
The heart has an internal electrical system that controls the rate and rhythm of the heart. Problems with this electrical system can cause the heart to beat too fast, too slow, with an irregular rhythm or to stop altogether. A cardiac arrest means a person's heart has stopped beating, this can occur for a number of reasons such as coronary heart disease, heart attack, choking, electrocution, drowning or there may be no known cause. A cardiac arrest is not the same as a heart attack, which occurs when the person's heart will usually continue to beat, but the blood flow to their heart is blocked. However someone that has a heart attack may then have a cardiac arrest.
Source: US National Heart, Lung and Blood Institute

According to the American Heart Association[4] CPR was developed in 1960, based on techniques developed by Peter Safar and James Elam in 1956 who invented

[3] http://www.publicguardian.gov.uk/docs/mca-code-practice-0509.pdf
[4] http://www.americanheart.org/presenter.jhtml?identifier=3012990

mouth-to-mouth resuscitation, and by Dr. Friedrich Maass who performed the first chest compression in 1891.

CPR may include compressions to the chest, with the aim to create artificial circulation by manually pumping blood through the body aimed at keeping oxygenated blood flowing to the brain and heart or inflating the lungs with a mask or tube. It may include using a defibrillator, a machine that gives the heart an electrical shock in order to re-start it.

Research into the effectiveness of CPR

Many studies have been carried out across the world as to the effectiveness of CPR and whilst too numerous to mention individually, generally the figures suggest that survival rate is poor in all age groups. Despite regular research and statistical gathering of evidence in the last few decades these figures have remained the same to date. This has led many practitioners working in the field to question the high use of a procedure that statistically demonstrates little or no benefit for many patients. The Resuscitation Council (UK) summarises an aspect of this research within their guidelines *Prevention of cardiac arrest and decisions about cardiopulmonary resuscitation*[5] stating that less than 20% of those where CPR is performed survive to go home. However The American Heart Association highlights within their 2010 statistical update[6] that whilst studies *"show varying rates of success, all are consistent in showing benefits from early CPR"*[7] therefore response times can positively impact on the outcome for the patient. The Resuscitation Council (UK) also highlights how higher nursing to patient staff ratio; regular monitoring, assessing and reviewing of a patient can impact on patient survival.

The decision making process of performing CPR

The British Medical Association, Resuscitation Council (UK) and the Royal College of Nursing's current guidance *Decisions relating to cardiopulmonary resuscitation*[8] states that cardiac arrest CPR will usually be performed unless there is evidence to indicate why it should not. It also states that where a person has the capacity to be involved in discussions about CPR then their views on this must be sought. When

[5] http://www.resus.org.uk/pages/poihca.pdf
[6] http://www.americanheart.org/downloadable/heart/1265665152970DS-3241%20HeartStrokeUpdate_2010.pdf
[7] http://www.americanheart.org/presenter.jhtml?identifier=4483
[8] http://www.resus.org.uk/pages/dnar.pdf

there are risks and burdens associated with performing CPR or there is only a slim chance of success the guidance highlights that patients may be willing to take this chance and therefore they should be involved with the discussion. However clinicians are not required to take action where they do not believe it will clinically be beneficial to the person. When the patients' wishes are not in line with the clinical judgment these factors should still be discussed. Where the patient would still wish CPR to be performed but the clinician believes this is not in line with their clinical judgment the guidance recommends that if this is still the case after discussion that a second medical opinion is sought or care is transferred to another Doctor or legal guidance is sought if the issue remains unresolved.

When CPR will not take place

There will be some patients where CPR is believed to be so overly burdensome that there would be little or no benefit and therefore a decision is made that it is not performed, also known as a Do Not Attempt Resuscitation (DNAR) order. Examples of making a DNAR order might be that the outcome would be the same whether it was performed or not – the patient would not survive - and therefore there is actually no decision to be made. For other patients there may be risks and burdens that are thought to outweigh any benefit, for example, if it is very likely that after CPR the person will be left with a degree of brain damage. Or where someone is terminally ill and an assessment leads to a view that CPR would only prolong that person's suffering as opposed to prolonging their life. For others a cardiac arrest may be an expected part of the person dying for example they are in the end stages of their life then consideration might be given to whether there should be a DNAR order.

DNAR Orders

The BMA, Resuscitation Council and RCN Guidance explains that where a DNAR is put in place because CPR will not be successful and the patient has not expressed a wish about CPR then there is no requirement to inform them that a DNAR is in place. However it states that this decision will be based on the individual and the factors applicable to that person and their current circumstances. Whilst the guidance states that most patients should be informed about a DNAR order that has been put in place, for others it may not be appropriate or viewed as beneficial for example, if they are in the end stages of their life and this information would be overly burdensome or offer minimal value. However where a person has been involved in their end of life

care planning then it would be expected that this planning includes them being informed about a decision to not perform CPR.

Indeed where there is an end of life care plan in place and cardiac arrest is deemed a risk then the discussion about CPR and the person's views on this are likely to have been sought anyway.

Responsibility to making a DNAR decision

The overall responsibility for a DNAR decision rests with the most senior healthcare professional responsible for the patient's care. When a DNAR decision is made it should be recorded clearly, together with the reasons for it and the names and designation of those involved in the discussion and decision. If no discussion takes place either with the patient or with those close to them, the reasons for this should be recorded. The use of an easily identifiable, dedicated form to record DNAR decisions is recommended[9].

Reviewing of a DNAR order

DNAR orders need to be reviewed by the relevant health professional in charge of the person's care and must occur when there are changes in the person's condition or their wishes. Healthcare providers may put in place further safeguards within policies with respect to how often the order is reviewed. When a DNAR order is put in place on admission, the BMA, Resuscitation Council and RCN Guidance recommends that this is reviewed at the earliest opportunity.

Decisions about quality of life

The BMA, Resuscitation Council and RCN state within their guidance *"Decisions must not be made on the basis of assumptions based solely on factors such as the patient's age, disability, or on a professional's subjective view of a patient's quality of life. Blanket policies that deny CPR to groups of patients, for example to all patients in a hospice or nursing home or to patients above a certain age, are considered unethical and are probably unlawful.*

When assessing whether attempting CPR may benefit the patient, decision-makers must not be unduly influenced by any of their own pre-existing (negative or positive) views about living with a particular condition or disability. The key issue to consider is

[9] http://www.resus.org.uk/pages/standard.pdf

not the decision-maker's view of the patient's disability or level of recovery that can reasonably be expected following CPR but an objective assessment of what is in the best interests of the patient, taking account of all relevant factors, particularly the patient's own views".

DNAR orders therefore cannot be placed on someone because of their presentation, age, diagnosis or disability, in line with the Mental Capacity Act, which makes clear that decisions cannot be made about a person only based on their condition, behaviour, age or appearance. This also means that whilst people's quality of life might form part of the decision making process, it is important that decisions are made based on the person's own perception (or those who know the person well) of the quality of their life and that judgements are not made about what constitutes quality of life based on the decision maker's own views.

Involvement of IMCAs in DNAR decisions

A DNAR order and therefore a decision not to perform CPR must be considered as serious medical treatment when the criteria are met. For example where there is a fine balance between the likely risks and benefits of CPR or because there will be serious consequences for the patient whether it is performed or not e.g. CPR may be successful but the person may suffer brain damage as a result. Alternatively they may require admission to an Intensive Care Unit (ICU), which may in itself raise questions that need to be asked as to whether this would be in their best interests. When the requirements for IMCA involvement are met then an IMCA must be instructed.

- IMCAs can be involved with a decision about a DNAR order because they have been instructed for a serious medical treatment decision for a person, and subsequently a decision about CPR needs to be made.
- IMCAs can be instructed because the DNAR is the treatment decision.
- IMCAs may come across a DNAR order for a person they are already working with and raise questions about this including whether there is a need to instruct an IMCA.

Further guidance about involvement of IMCAs in DNAR decisions

Within the 'Joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing on Decisions relating to

cardiopulmonary resuscitation" the following is stated:

"It can be argued that a decision not to attempt CPR because it will not work will not have 'serious consequences' for the patient, because the patient will die with or without attempting CPR. For this reason, in our view, an IMCA does not need to be called when it is clear to the medical team that CPR would not re-start the patient's heart and breathing for a sustained period"

"Nevertheless, neither the Act, nor the code of practice, differentiates between decisions made purely on clinical grounds (i.e. because the treatment is unable to achieve its clinical aim) and those that involve broader best-interests considerations and so it needs to be acknowledged that there is still some uncertainty in this area. Where there is genuine doubt about whether or not CPR would have a realistic chance of success, or if a DNAR decision is being considered on the balance of benefits and burdens, in order to comply with the law an IMCA must be involved in every case. If a DNAR decision is needed when an IMCA is not available (for example at night or at a weekend), the decision should be made and recorded in the health record. The decision should be discussed with an IMCA at the first available opportunity. An IMCA does not have the power to make a decision about CPR but must be consulted by the clinician in charge of the patient's care as part of the determination of the patient's best interests".

MCA 2005 Guidance

The Mental Capacity Act 2005 Code of Practice (5.31) states that, *"All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death".*

When best interests decisions are being made about a DNAR order, as there is evidence to suggest the person may survive, it is important that the clinicians consider the above where they are responsible for the decision. Importantly though this should be considered by the IMCA in terms of their representation of the person.

Cultural and religious factors

Many religions are explicit as to their views on how life should be preserved, when medical intervention should cease as well as when it is appropriate to continue. When working on a timely decision and with someone who may be unable to communicate effectively, being able to research differing religions and their belief systems can prove difficult but it is important to ask whether it is known not only if a person was born into a faith (or converted to a faith) but whether they practiced this. It is important not to assume that merely belonging to a religious group means someone either agrees or practices this faith. Equally a person 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. The level of intervention a person would want should always be considered if it is an option within a best interests decision.

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.

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 is likely to impact on gathering this information particularly when it may be an urgent decision, 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: Why has a DNAR order been put in place?

Q: What risk and/or burdens will the person face if CPR is performed?

Q: What is the chance of CPR revival for the person if they have a cardio respiratory arrest?

Q: Are there known illnesses or medical problems that will impact on the outcome of a decision to perform CPR?

Q: What is the overall condition of the person's health and what effect will performing CPR have on this i.e. is it likely the person will have more physical health

or care needs?

Q: Has the person's faith, beliefs or culture been considered in terms of levels of medical intervention and to what level the person would want these to be considered?

Q: When will the DNAR order be reviewed?

Q: Is there an advanced decision to refuse treatment that is applicable to this decision or have attempts been made to find one?

Please note some of these questions are sourced from the BMA[10]

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 about CPR?

Q: Has the person expressed a preference in the past or now about the levels of medical intervention?

Q: Does the person have any concept or understanding of death?

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: With respect to any risks or burdens from CPR on the person how will this affect their daily life including any psychological, emotional and physical factors that need to be considered?

Q: If the person would have increased needs if CPR were performed could these be looked after in their current environment and/or how would the person react to a change in needs?

Points to highlight within a report:

- The physical, emotional and psychological impact on the person
- Expressed preferences of the person about CPR and or a decision not to resuscitate
- 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
- Relevant legal or medical guidance

[10] http://www.bma.org.uk/ethics/cardiopulmonary_resuscitation/CPRpatientinformation.jsp

Further guidance & resources

National Heart, Lung and Blood Institute

www.nhlbi.nih.gov

The Resuscitation Council UK

www.resus.org.uk

The British Medical Association

www.bma.org.uk

The Royal College of Nursing

www.rcn.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.

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