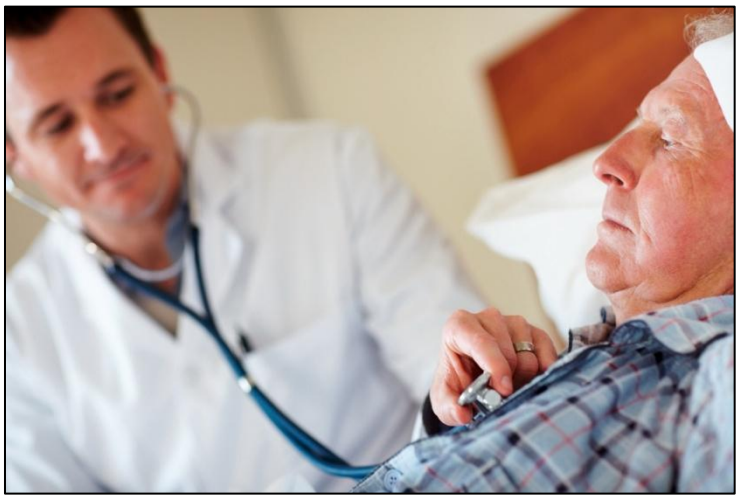
Serious Medical Treatment Decisions

BEST PRACTICE GUIDANCE FOR IMCAs

CHEMOTHERAPY



action for advocacy

IMCA Support Project

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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 IMCA's 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 IMCA's work.

The guidance will cover SMT decisions about using chemotherapy to treat cancer 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 where further information about IMCA instruction or writing IMCA reports 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
- major consequences such as stopping life sustaining treatment or amputation

[1] www.actionforadvocacy.org.uk
[2] http://www.legislation.gov.uk/uksi/2006/1832/regulation/4/made

- 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 whoever 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.

Chemotherapy

Chemotherapy is a common treatment for cancer. Cancer is a disease whereby the proposed treatment is highly likely to be 'serious medical treatment' as defined in the Mental Capacity Act.

When a person develops cancer, the normal cells change so that they grow in an un-controlled way forming tumours. If left untreated, this can cause serious problems as the cancer can spread through the body via the bloodstream or lymphatic system.

After cancer has been diagnosed the consultant will consider which treatment(s) is appropriate for the particular individual as there are a number of different treatments and combination of treatments for cancer, including chemotherapy, which may be effective. The type of treatment will depend on the type of primary cancer (where the cancer started) and whether it has spread. Specialists will rely on research which has shown what type of treatment is most effective for particular cancers.

[3] http://www.publicguardian.gov.uk/docs/mca-code-practice-0509.pdf

What is Chemotherapy?

Chemotherapy is treatment with anti-cancer drugs, given to destroy or control cancer cells. A single drug may be given or several different drugs may be given together. This is called combination chemotherapy. The aim of the treatment will depend on the type of cancer you have and how advanced it is.[4]

The term chemotherapy, in cancer treatment, means using cytotoxic (cell killing) drugs. The drugs enter the bloodstream and therefore reach all parts of the body, destroying cancer cells.

Who can have chemotherapy?

When cancer is diagnosed the consultant will consider which treatment is appropriate for the particular individual as there are a number of treatments and combination of treatments which may be effective.

Whether chemotherapy is suitable for a person depends on a number of factors:

- the type of cancer
- the 'grade' of the cancer cells
- where in the body the cancer started
- the general health of the person
- whether the cancer has spread to other areas

The 'grade' of the cancer cells refers to how well developed the cells look when examined under a microscope. The more normal a cancer cell looks, the lower its grade. Cells are usually classed as low, medium or high grade and sometimes referred to as grade 1, 2 or 3 where grade 1 is low grade. If a cancer is classed as a low grade, it means it is less likely to spread than a high grade one. Tumours are made up of billions of cancer cells.

Sometimes when a person has a terminal illness, palliative chemotherapy is given to relieve symptoms. For example, if it's been determined that the cancer cannot be cured, it may be considered beneficial to give chemotherapy treatment with the aim of shrinking the tumour to alleviate the physical symptoms.

[4] http://www.royalmarsden.nhs.uk/cancer-information/treatment/chemotherapy

How is chemotherapy treatment given?

A person may be given one chemotherapy drug or a combination of different chemotherapy drugs. In all cases, the drug (s) must be absorbed by the blood and transported throughout the body.

The three main ways of administering chemotherapy are:

- intravenously (through a drip or injection)
- orally – tablet form or capsules
- via an infusion pump (when a line (tube inserted into a vein) is set up to deliver the chemotherapy drug)

There are other ways such as injecting:

- intramuscular (into muscle)
- subcutaneous (into fat)
- intra-arterial (into an artery)
- into a body cavity
- directly into the tumour

Sometimes chemotherapy is combined with other treatments such as:

- surgery
- radiotherapy
- hormone therapy
- biological therapy

For example, chemotherapy may be given before surgery to help shrink the tumour or after radiotherapy to eliminate any possible remaining cancer cells.

Chemotherapy may also be given more than one way; for example, intravenous injections may be combined with tablets. More information about the various ways in which chemotherapy can be given can be found at the patient information section of the Cancer Research website http://www.cancerhelp.org.uk/about-cancer/treatment/

All patients should have a **chemotherapy treatment plan** (sometimes known as a protocol) which will include, for example, the diagnosis, proposed treatment drugs and method of delivery, planned cycle of treatment, tests required pre chemotherapy and during treatment and how many 'rest' periods are planned.

Duration of treatment

The length of the treatment will depend on how well the cancer responds to the treatment. It can take several months to complete a course of chemotherapy. The chemotherapy will be given in a series of treatment sessions which are then followed by a rest period which allows the healthy cells and tissues to recover. If treatment is given via an infusion pump, whereby an electronic device is used to control the administration of chemotherapy drugs over a period of time, it may be delivered slowly over a period of several days or weeks. It is possible in some situations to take a pump home for continuation of treatment there.

Most chemotherapy treatment can be given to people as a day patient but some people may require a short stay in hospital. If a higher dose of chemotherapy is to be given it may require a longer stay in hospital. Each treatment as a day patient usually lasts between 4 – 6 hours but could be longer if the treatment is more complex.

Monitoring the treatment

Various tests, including blood tests will be carried out before treatment commences. Tests on the heart are often carried out.

During treatment cycles tests will monitor the effect of the chemotherapy on the body. For example, X-rays may be taken to examine the effect of the treatment on any tumours. Sometimes as a result of these tests the chemotherapy plan may be changed.

The Chemotherapy Care Pathway

The National Chemotherapy Advisory Group has produced guidance on: 'Chemotherapy Service in England: Ensuring Quality and Safety' Published in August 2009. It says in chapter 2.1 that *'The chemotherapy process can be considered as a care pathway which starts at initial referral to an oncologist and ends with completion of treatment and the development of a subsequent care plan'*.[5]

The above guidance also emphasizes the importance of pre-decision assessment so that the decision to offer chemotherapy treatment is a robust one and based on

[5] 'Chemotherapy Service in England: Ensuring Quality and Safety' http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_104501.pdf

excellent knowledge of the individual patient. '*Assessment will include the extent of a patient's disease, their general fitness or frailty, any existing co-morbidities and any investigations required to ensure safe delivery of chemotherapy or as a baseline for measuring response to treatment'*

Information

The Royal Marsden's Patient Information Service[6] produces a series of booklets aimed at patients and carers which are a useful resource for IMCAs. IMCAs may find 'Chemotherapy your questions answered'[7] from the Patient Information Series particularly useful.

Generate, an organisation which supports people with learning disabilities, worked in partnership with Mencap to produce the EasyHealth[8] website which offers Easy Read information booklets and pictures on health topics.

The Royal College of Psychiatrists has a publication entitled 'Getting on with Cancer'[9] which follows the story of Veronica, a woman with Down's syndrome when she is diagnosed with cancer.

Medical Side Effects, Risks and Burdens

Complications can occur with any medical procedure and it is important to have some understanding of what the risks may be although it should be noted that these risks are a general overview and may increase or decrease depending on the individual's history, current presentation or assessment.

Chemotherapy drugs destroy cancer cells by damaging them and in the process of doing this normal healthy cells may be damaged which can cause side effects. Usually the side effects are temporary as healthy cells can quickly return to normal. The side effects for each individual will depend on the type of chemotherapy; some will be fairly immediate whilst others may take a while to develop.

Possible side effects

- flu-like symptoms

[6] http://www.royalmarsden.nhs.uk/cancer-information/patient-information
[7] http://www.royalmarsden.nhs.uk/cancer-information/patient-information/booklets/chemotherapy.pdf
[8] http://www.easyhealth.org.uk/health-problems-and-illnesses/cancer
[9] http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1901242846.aspx

- gum/nose bleeds/unusual bleeding
- mouth ulcers
- vomiting
- raised temperature
- diarrhoea
- difficulty with breathing
- anaemia
- bruising
- tiredness
- changes in appetite/taste
- dry/sore hands and feet
- hair loss/thinning
- damage to ovaries/testicles

Some rarer side effects:

- blood clots
- allergic reaction
- irritation to bladder
- changes in kidney function
- changes in liver function
- nervous system symptoms
- tissue damage
- death

Rare long term risks

- developing second cancer due to chemotherapy drug
- damage to the heart muscle

The National Confidential Enquiry into Patient Outcome and Death[10] : (NCEPOD) 'Systemic anti-cancer therapy: For better, for worse?' looked at the care of patients who died within 30 days of receiving systemic anti-cancer therapy (SACT) and investigated whether the death was due to the toxicity of the treatment, progression of the cancer or another unrelated cause. A total of 546 cases were reviewed. In relation to the decision to treat, the researchers found that in 19% of cases where the person had died within 30 days of receiving SACT, the advisors' opinion was that the

[10] NCEPOD 'Systemic anti-cancer therapy: For better, for worse?' http://www.ncepod.org.uk/2008sact.htm

decision to treat was inappropriate. In 27% of cases the advisors believed that the SACT had caused or hastened death.[11]

Benefits

Chemotherapy can potentially:

- reduce the number of cancer cells that spread to other parts of the body therefore reducing the risk of cancer returning later
- be used to shrink tumours making less invasive surgery possible
- prolong life
- be used palliatively to relieve symptoms

Ethics

One ethical consideration when a decision is being made about whether or not to treat a person using chemotherapy is if there is a degree of uncertainty about whether the treatment will prolong the person's life and there is evidence that the person will have difficulties in understanding and dealing with the side effects. Is a decision to provide treatment always in the person's best interests? If the treatment means that the person may live an additional 4 months, for example, would it be in their best interests if it means they have to endure significant side effects? The decision will be based on risks versus benefits and sometimes this may be quite finely balanced.

There may also be issues related to the use of chemotherapy as a palliative treatment and whether this is effectively prolonging a person's death.

Quality of life is an individual issue, what is quality for some, may not be acceptable for others. When quality of life is raised as a factor in decision-making, it is important to ensure that it is based on the knowledge of that individual whom the decision is about and what is known about what they perceived as quality of life and not what is perceived as quality of life for the medical professionals, family, carers or the advocate involved within the decision making.

[11] Pg17 Summary NCEPOD 'Systemic anti-cancer therapy: For better, for worse?' http://www.ncepod.org.uk/2008report3/Downloads/SACT_summary.pdf

Cultural and religious factors

A patient's religious or cultural beliefs may impact on the decision 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. All societies have different cultures and this is seen through traditions, beliefs, language, where a person has lived, their experiences, surroundings as well as interactions with others, these will all impact on the way we see and experience the world and ultimately what our own culture is.

It is not possible to find this much detail from a person when working as an IMCA due to both time constraints on the decision making process and the ability to form a long term advocate/client relationship as well as communication or comprehension factors. However IMCAs should consider the above when meeting with the client as well as speaking to others. Culture can sometimes narrowly be viewed as only being connected to religion. Similarly it is only to be 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 effectively.

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. Again 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 system 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 also important not to assume that merely belonging to a religious group means someone either agrees or practices this faith.

Questions to ask the Decision Maker

Q: How has the person been supported to understand the decision?
Q: What are the main treatment options?
Q: What are the benefits of each of the options?
Q: What are the risks for each of the options?
Q: What are the risks if no treatment is provided?
Q: What method will be used to deliver the chemotherapy treatment?
Q: What are the known side effects from the particular drug(s) which will be used?

Q: Is anything known about the person's medical history which may make them unsuitable for chemotherapy?

Q: What can be done to help the person cope with any side effects?

Q: Will the person need to travel to a specialized chemotherapy unit?

Q: Will the person need a stay in hospital when receiving the treatment or will they be a day patient?

Q: How long will each treatment session last?

Q: What is the chemotherapy treatment plan for the person?

Q: Can the treatment be given at the person's home?

Q: Are there any issues related to potentially reduced immunity?

Q: How will the chemotherapy affect the person's quality of life?

Q: What are the survival rates for this type of cancer treated with this type of chemotherapy?

Q: If it is proposed to give palliative chemotherapy, what are the benefits (likely survival gain, pain relief etc) and the limitations?

Questions to ask the person and those who know the person

The person's views

- Can the person give their views on whether or not they would want to have chemotherapy or have they indicated their views in the past?
- Have they been given information in an appropriate format that will give them the opportunity to understand what is involved?
- Did the person make an advanced decision to refuse treatment which is applicable to their current situation?

Any previous treatment

- Has the person visited hospital previously either as an outpatient or inpatient and how did they deal with the experience?
- Has the person received chemotherapy previously and if so, how did they react to it?
- Has the person had experience of receiving injections in the past and are there any issues related to needles?

The effect of treatment on the person

- Which activities does the person value and what affect would not being able to temporarily do them have on the person?
- How does the person usually deal with the symptoms of any illnesses?

- How will the person cope with the possible disruption to their usual routines?

Care/support

- What support will be needed/how will it be provided both at the hospital during the treatment and at home afterwards?
- Has the person indicated any preferences in terms of the support they will need (eg who they would want to accompany them to hospital)?
- If the person lives in a care home, are the staff fully aware of the likely side effects and how the person will be supported to manage them?
- If the person lives at home with the support of carers going into the home, what plans are in place to enable the person to safely manage any side effects?
- If the decision is not to treat, who will be responsible for establishing the end-of-life care plan?

Points to highlight in the report

- the expressed views/feelings/beliefs of the person including any advanced decision to refuse treatment relevant to the particular circumstances
- the views of others – carers/family/professionals in terms of the actual treatment but also their perception of what decision the person would have made if they could
- any issues related to the person's likely ability/inability to cope with the treatment and aftercare
- information about diagnosis, prognosis and proposed treatment options
- known benefits, risks, burdens, limitations of the treatment
- least restrictive option
- relevant legal (including MCA) or medical guidance
- any ethical issues
- any religious or cultural issues

Further guidance & resources

Macmillan
http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Chemotherapy/Beingtreated/Havingchemotherapy.aspx

Cancer Research UK:
http://www.cancerhelp.org.uk/about-cancer/treatment/chemotherapy/about/chemotherapy-and-cancer

National Institute for Clinical Excellence (publish clinical guidelines)
www.nice.org.uk

UK National electronic library for health
www.library.nhs.uk

British Committee for standards in Haematology
http://www.bcshguidelines.com/4_HAEMATOLOGY_GUIDELINES.html

Royal Marsden Hospital Patient Information Service
http://www.royalmarsden.nhs.uk/cancer-information/patient-information/booklets

Royal College of Nursing – standards for infusion therapy
http://www.rcn.org.uk/__data/assets/pdf_file/0005/78593/002179.pdf

National Chemotherapy Advisory Group – Chemotherapy Services in England – ensuring quality and safety
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_104501.pdf

The Gold Standards Framework – enabling a gold standard of care for all people nearing the end of life
http://www.goldstandardsframework.nhs.uk/

EasyHealth – website with easy read health fact sheets
http://www.easyhealth.org.uk/

Royal College of Psychiatrists – Books Beyond Words
http://www.rcpsych.ac.uk/publications/booksbeyondwords.aspx

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
Dental Treatment
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

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