DECISION-MAKING WITH VULNERABLE PATIENTS DURING A TIME OF CRISIS

During this Covid-19 pandemic, it is essential that as clinicians we promote and support good decision-making about care. Understanding a patient's wishes and informing them of onward care processes, such as separation from family, potential from intensive care, as well as the risks of not attending hospital with an untreated myocardial infarction or pneumonia, are all part of assessment and, where relevant, obtaining informed consent.

Take 5 – Involve – Decide

Take 5 – taking time to reflect in difficult circumstances

The pressure of a pandemic means it's even more important to take a few moments to check decisions against potential biases and assumptions.

As is always the case for complex decisions, we must watch out for subtle assumptions, bias and pressure. These could include:

- Patients and their clinicians fearing the risk of Covid-19 infection from a hospital admission, where the patient still wants and would benefit from acute care.
- Assumptions relating to quality of life for socially vulnerable or older individuals in our care.
- Concerns/assumptions about resource pressures.

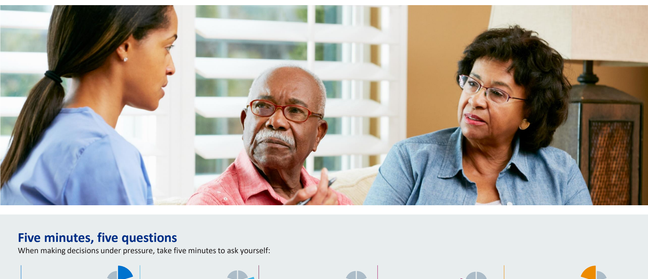
A pandemic does not change the fundamentals of care planning.

Conversations are about access to treatment.

Involve & Decide

Care planning is complex and sensitive, and is usually done in the context of progressive disease and anticipated deterioration. Care planning is always voluntary. It is done with people, not for people.

- Involve the individual and be clear and open: what is the decision about?
- If your decision is outside your usual area of expertise, ask others such as a safeguarding lead for help and balance.
- Decision-making presumes that the patient has capacity. If you are concerned that a patient may lack capacity, take steps to assess this formally. This may be through your safeguarding lead in your organisation.
- Remember: you cannot conclude that a person has been unable to make a decision just because their choice seems unwise. Your role is to support them to make their own decision. If the patient lacks the capacity to make the specific decisions, involve any attorney, relevant family, carers or advocates, and social workers to learn more about the patient's wishes. You can also discuss with your safeguarding lead in your organisation too.
- Advance Care Plans, if they exist, should be reviewed and used. If the patient has an advance decision to refuse treatment, this should be reviewed with them. (Note that Advance Care Plans come in several forms: advance statements, advance decisions to refuse treatment, LPAs for health and welfare and, for Londoners, Coordinate My Care records).
- When a decision is made, record it fully. Other colleagues will rely on your record if the patient is no longer able to speak for themselves, and if family and carers are not contactable.
- This is also in line with the Advance Care Plans Marie Curie have been supporting with their dedicated Advance Care Planning Service in some parts of London.



Five minutes, five questions

When making decisions under pressure, take five minutes to ask yourself:

1. Am I upholding this patient's human rights?
2. Am I starting from a point of providing access to the care this individual needs and would prefer?
3. Who have I involved in this decision?
4. Are assumptions about resource limitation influencing my decision making?
5. Am I recording this decision comprehensively and appropriately?

It's good practice to talk things through with a colleague. That's why there's more specialist support available.

Decisions

Decisions about the value of a treatment involve four elements:

1. Is it wanted? (Consent)
2. Will it work? (Efficacy)
3. Is it suitable? (Benefits & harms)
4. Is it available/is transfer wanted or beneficial? (Resources/preferred location)

Care planning is about access and establishing preferences. Assumptions about resource limitation should not influence your decision making.

Before any resources based decision making is considered, all options to decompress the system or improve the resources within in must have been explored locally, regionally and nationally and all options for local, regional and national mutual aid must have been thoroughly explored and be inaccessible. Therefore the chief executive and executive clinical leadership of the provider and system, the regional director and regional clinical leadership and national directors must be involved in determining whether all feasible national, regional and local options have been exhausted.

"What Matters Most" Conversations

Towards the end of life, providing care that matches **what matters most** to people becomes increasingly important. Discussions about what matters most can begin within individuals' networks of family and friends, and be picked up by health and social care professionals.
Four main principles for health and social care professionals' consideration:

1. Seeking to discover what matters most in life to this individual. How they see themselves, what is important to them and what makes life worth living.
2. Seeking to discover what are the most important social connections for this person and how such connections could help in the event of life being restricted through illness.
3. Seeking to discover in the event of illness, how health and social care decisions can be used to support what matters most to this person. This includes some plans about urgent treatments to be embraced or avoided. Considerations might include what they would wish not to live without and what they think would make their life intolerably difficult.
4. In the light of the above, and with access to clear, realistic information about likely treatment options and outcomes, to help individuals map what treatments would most likely to match their own individual needs and hopes. The process of Planning Ahead enables professionals to focus their care on what matters most to people.

whatmattersconversations.org

Acting in a person's best interests

Best interest decisions look at someone's welfare in its widest sense, giving weight to the person's previous wishes, beliefs and values to influence a judgment about the benefits and harms of any course of action.

- Consider the investigations and treatments in question, what they involves and their prospects of success. (Efficacy)
- Consider the likely outcome for the patient and consider what they would have wanted. (Benefits and harms)
- Consult others who care for the patient or are interested in the patient's welfare, in particular for their view of what the patient's attitude would be.

* adapted from Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67. Also refer to the Mental Capacity Act (MCA): https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice

These principles must hold and guide best interest decisions at all times.

Avoiding harm and focusing on equality

This summary reminds us to consider duties to prioritise equal access with our duty to avoid harms from ill-considered treatments. For socially vulnerable people, we must take care not to make assumptions about someone's quality of life, its value to them and us, and respect their choices. We must avoid simplistic categorisation.

Social vulnerability to discrimination?

Remember:
- Duties of Equality & Fairness
- Default in favour of life (the chance to have a future)

Ensure clear understanding of our own vulnerabilities as clinicians to:
- Subconscious false assumptions about someone's wishes or potential for benefit
- Judgements clouded by a person's mental ill-health
- Mistaken assumptions from disabilities, including intellectual impairment from the autistic spectrum or neuro-disabilities like cerebral palsy, or assumptions from being homeless, drug dependent or simply alone and unable to advocate for oneself.

Remember:
Many people sit between these groups and require specific reflection and consultation

Reflection & Consultation

Physical vulnerability to dying badly

Remember:
- Avoid harms from unnecessarily medicalised death
- Default in favour of quality (a life that a person would want)

Ensure clear understanding by the patient and family that:
Many treatments can be given in the community and don't need hospitalisation. Emotional, social and spiritual needs may be threatened, compromised or lost by a given course of action. These could include:
- Distressing physical invasions and iatrogenic problems
- Lost contact with family and friends
- Unmet cultural and religious needs

** Physical morbidity from hospitalisation, such as muscle loss and reduced neuromuscular function, which is universal following a period of critical illness and may never regained.

** Non-physical morbidity such as post-traumatic stress and cognitive dysfunction. which is also common after a period of critical illness.

A considered balance of consent, efficacy, benefits & harms

Further national resources

BMA Ethics Guidance:
https://www.bma.org.uk/advice-and-support/covid-19/ethics/covid-19-ethical-issues

NHS England and NHS Improvement (2021) Operational Guidance:
Operational-guidance-for-regions-on-using-all-of-our-national-health-system-people-and-resources-13-January-2021.pdf (cheshireandmerseysidepartnership.co.uk)

NICE Covid-19 information:
https://www.nice.org.uk/covid-19

Government guidance on supported living and home care:
https://www.gov.uk/government/publications/supported-living-services-during-coronavirus-covid-19
https://www.gov.uk/government/publications/coronavirus-covid-19-providing-home-care

Resources from other primary care professionals
https://reimaginghealth.com/a-difficult-conversation-about-covid-19-care-planning/

Difficult Conversations Framework, supported by the RCGP:
https://www.difficultconversations.org.uk/covid-19-faqs

RCGP Daffodil Standards for Advanced Serious Illness and EOLC:
https://www.rcgp.org.uk/daffodilstandards

RCGP Ethical guidance on COVID-19 and Primary Care:
https://elearning.rcgp.org.uk/mod/page/view.php?id=10557

RCGP EOLC COVID resources:
https://elearning.rcgp.org.uk/mod/page/view.php?id=10537

Patient information

Royal College of Physicians Patient Information, Understanding Treatments and Outcomes in Hospital and Critical Care,
www.criticalcarenice.org.uk/patient-information

GSTT video resources:
Planning your care
https://www.youtube.com/watch?v=prpgu2PmYwk
Uncertain recovery
https://www.youtube.com/watch?v=rpQNthGsADI
Making decisions about treatment
https://www.youtube.com/watch?v=8SBTSJL6Ic4
Cardiopulmonary resuscitation
https://www.youtube.com/watch?v=1pJ1TKNkwH0
All available at
http://www.guysandstthomas.nhs.uk/Let'sTalk

Legal resources

Mental Capacity Law and Policy:
https://www.mentalcapacitylawandpolicy.org.uk/resources-2/covid-19-and-the-mca-2005/