NHS South East London Clinical Commissioning Group
Health Innovation Network South London
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St Christopher's More than just a hospice

ADVOCACY & DECISION-MAKING WITH VULNERABLE PATIENTS DURING A TIME OF CRISIS

During this Covid-19 pandemic, it is essential that as clinicians we advocate for our patients, and 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 sequelae 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- Concerns/assumptions about resource pressures, which may be incorrect or out-of-date.

A pandemic does not change the fundamentals of care planning.

First and foremost, we are our patient's advocate. 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 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.
- 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 next attorney, relevant family, carers or advocates to learn more about the patient's wishes.
- 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.

Five minutes, five questions

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

1. Am I being an advocate for this person, first and foremost?
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 resources or wider system pressures influencing me, and if so, how can I check?
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. It should never start with questions about availability or resources.

Should our community ever reach the point where decisions depend on available resource in addition to clinical necessity, these decisions will be made with informed colleagues and an appropriately constituted Ethics Committee.

Support for complex cases & ethical questions in the community

GPs in the community can already access a range of existing advice routes, including established on-call palliative medicine, psychiatry, and elderly care consultant teams. In south east London, specialist palliative care advice is available 24/7 through existing local palliative care services.

GPs are now able to access a supportive professional conversation from experienced colleagues through Consultant Connect. For very complex cases, a new South East London Mental Health and Community Ethics Forum has been created.

'Call a Colleague' – Primary care: complex/ethical treatment decisions
8am – 8pm, 7 days a week, via Consultant Connect

Most of us will have access to colleagues in our GP practice who can help in the first instance. Where this might not be the case, support with decision-making is available from another designated group of local GPs.

To access this support, select Primary care: complex/ethical treatment decisions on the Consultant Connect app.

It is the role of this colleague to offer a supportive professional conversation and decision support, not clinical advice. The final clinical decision will remain with the clinician responsible for the patient's care.

South East London Mental Health and Community Ethics Forum
3.30pm, Mon – Fri

Working closely with SLaM, a South East London Mental Health and Community Ethics Forum has been established that can discuss very complex scenarios with a range of specialists, including legal and lay representatives. Its members are experienced in dealing with very complicated decision-making when there may be concerns about mental capacity, vulnerability and end-of-life questions. It will also support reflection and learning across our community.

This forum meets at 3.30pm daily. Please note: if an out-of-hours decision is required, i.e. it cannot wait until the next day, this means the clinical situation is urgent, and the default position should be to follow your existing out of hours processes, for example assessment in an acute setting.

These new models have been set up in the context of Covid-19 but are designed for all patients where useful.

We expect that these new routes would be used in conjunction with existing support, such as specialist on-call palliative care advice.

The Ethics Forum can be accessed via the Call a Colleague service, by selecting 'Primary care: complex/ethical treatment decisions' on Consultant Connect.

Acting in a person's best interests

Best interest decisions look at someone's welfare in its widest sense, taking in social, psychological, cultural and spiritual factors that 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 what the outcome for the patient is likely to be, trying to put yourself in their place to ask what their attitude is or would be likely to be. (Benefits and harms)
- Consult others who look after 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

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

Advocating for patients by 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 local resources

Covid-19 Resources for Primary Care
The SEL website with primary care resources is at http://gp.selondonccg.nhs.uk/

Lambeth Advance Care Planning Consortium
https://www.healthwatchlambeth.org.uk/advancecareplanning

https://www.healthwatchlambeth.org.uk/lambethadvancecareplanningproject

Further national resources

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

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/covid-19-residential-care-supported-living-and-home-care-guidance

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

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=rpQNlhGsADI

Making decisions about treatment
https://www.youtube.com/watch?v=B5BT5JL6kr4

Cardiopulmonary resuscitation
https://www.youtube.com/watch?v=1pJ1TKNkvH0

All available at
http://www.guysandstthomas.nhs.uk/LetsTalk

Legal resources

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

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