



Supporting People to Make Choices about their Future Care and Treatment

Dr. Fiona Morrissey, Disability Law
Researcher

Adjunct Lecturer, NUI Galway



Overview

- Introductory Comments/Questions
- Substitute Decision-Making Vs Supported Decision-Making
- Why is it Important to Support a Person to Make their own Decisions about Future Care/Treatment?
- How can Healthcare Workers Support a Person to think about their Future Care and Treatment?
- Steps to Support People to make Care and Treatment Decisions
- What do Healthcare Workers Need to Consider?
- What should Person Consider when making Decisions about Future Treatment/Care?



- Supporting people to make decisions about future treatment and care (advance care planning) enables them to continue to have a **'voice'** in their own care
- Prevents conflict which can arise where person's wishes unknown. Recent cases in courts between family and hospital
- Allows future treatment to be provided in accordance with **'my' wishes**. Respect for the **'voice'** the person. Better for all us!

Substitute Decision-Making Vs Supported Decision-Making

- **Substitute decision-making**-treatment/care decisions made for person by others in what is sometimes deemed to be in his/her **'best interests'**
- Often well intentioned with aim of protecting person. However, sometimes good intentions do not help people!
- May be **informal or formal** e.g. family members, HCWs, or appointed by court under wardship
- Next of kin do not have legal authority to make decisions, consulted in practice
- Consistently taking away opportunity to make decisions, **damaging & disempowering**
- Decisions make up our identity, life values
- By not supporting people to make their own these decisions, we are denying them **right to make healthcare choices, live as they wish**

Supported Decision-Making: A Natural Process We all Engage In



- We all need support to make decisions in different areas/times in our lives
- Depending on decision, timing, we might need more support to make some decisions than others
- We often turn to **people we trust** to help us to make decisions
- Supporter never makes decisions on our behalf, or instead us
- Some people may need more support than others to make decisions. E.g. people with cognitive disabilities
- In SDM, **person at centre of all decisions**, move away from 'best interests' towards will & preferences of person. ADMA reqs
- Focus on **supports** person needs to make treatment/care decision **rather than deficits** in capacity

Why is it Important to Support a Person to make Decisions about Future Care & Treatment?



- **Better healthcare outcomes**
- Sense of **control**
- Allows person to be treated in accordance with wishes/values
- Reduces decision-making burden on family, HCWs
- Enhances therapeutic relationship
- **Empowerment**
- Improves decision-making skills
- Increased sense of **choice & respect**
- **Autonomy, dignity** re: treatment/care
- Provides **important information, clarity**
- Reduces need for **coercion**, non-consensual treatment, which causes additional trauma
- Improves **quality of life/care**
- Enhances **recovery** particularly in mental health, maternity care
- Allows person to continue to have a '**voice**' in treatment/care, or through **trusted person**
- **Basic human right** to make healthcare choices

Meaningful Support



- **Consciously use supported decision-making approach**
- Supports may be **informal or formal**
- May be very simple like **communicating information** in way person understands
- Consistently asking person **‘what they want’?**
- **Communicating, listening, engaging** with person
- Level of support needed to make future treatment/care decision depends on **person, context**
- Support should be based on individual circumstances, tailored to person, never imposed
- **“Nothing about us without us”**

How can Healthcare Workers Support a Person to think about their Future Treatment and Care?

- Research shows **people want/need support** to plan for future treatment/care
- Completion rates increase dramatically where support (Swanson, 2006)
- Support does not have to be from HCW, can be independent
- Good practice to '**start conversation**', **engage with person** on future care/treatment. Prevents problems later
- **Initiate** as part of overall **conversation** on person's values, care plan
- Give person **information** they need in format they understand
- **Time** to weigh up information, make decision, refer for independent support if needed (e.g. advocacy)
- Allow person to talk to **trusted people** close to them
- **Not just once off process**
- **Engage** with person's wishes on ongoing basis, but particularly after health status changes

Steps to Support People to make Treatment/Care Decisions

- Start ACP conversation with **everyone** (start with yourself!)
- Focus on **supports** person needs to make decision not deficits
- Important not to make blanket assumptions about capacity, age
- **Timing** critical
- **Early as possible**, not in emergency crisis situations where person/family too distressed
- **Information** in visual format or simplified language if necessary
- Get person to think about **what they might want/who they would trust**
- **Time** to make decision without pressure or undue influence. Decision should be made outside hospital/care setting if possible
- Allow person to talk to people close to them, ask them if they want anyone to be present
- Give them **Think Ahead Form!**
- If after taking all steps, still not clear, try to **determine what person's decision might be in circs**, talk to people close to person re: values, previously expressed wishes re: treatment/care
- Important to document conversations, and supports given, so no confusion

What do Healthcare Workers Need to Consider?

- Fine line between supporting and influencing
- Need to be conscious that you are in position of **power** over person, so **try to avoid influencing** as far as possible, ensure it is person's decision
- Give person **information** in **non-bias manner, format they understand**, ensure understand information, give them time to consider it, ask questions,
- Ensure **decision based on person's wishes** rather than **what you think** is in their '**best interests**' or **what their family wants**
- Try to resolve conflicts, alleviate fears, and support person as far as possible to make own treatment/care decisions,
- Continue to support them even if they do make decision you disagree with!

What should Person Consider when making Decisions re: Future Treatment/Care

- Start by making your own ACP!
- Discuss
- **Who would you trust** to communicate your wishes?
- Significant percentage of people do not have someone they trust (Morrissey, 2015)
- **Values** re: how you want to live/die well
- **Treatment preferences**-preferences you may have in re: **treatment you do/do not want**. May be based on past experience of side effects
- Wishes re: **life sustaining treatment** e.g. artificial nutrition/hydration, CPR, if there is no prospect for recovery, quality of life issues
- **Place of care preferences**, wishes on where you would like to be cared for e.g. hospital, at home or in hospice
- **Other life choices**, who will look after children, pets, house if you are in hospital



SECTION 2. Care Preferences

This section provides key information about you that can be used to inform your medical treatment and care in case of emergency.

This information should be shared with: (Please tick all that apply)

- Family Loved Ones GP, Nurse, Carer Other

- How would you like to be cared for if you were ill?
- Who would you like included in discussions about your medical condition or care?
- Are there cultural/spiritual preferences or religious beliefs that you would like the healthcare staff to consider in caring for you?

These are important questions. They can be answered here so that you are given the best possible care and consideration by the staff at a hospital or in another care setting.

This part of the form has three separate sections.

1. The first section deals with your care preferences should you become ill and are unable to communicate your wishes.
2. The second section is an Advance Healthcare Directive. This allows you to set out your preferences about medical treatments you **do not want** to receive in the future in case you cannot communicate your wishes at that time. It also allows you to nominate someone, called a **Designated Healthcare Representative**, who you have authorised to interpret or make your healthcare decisions. If you have appointed an **attorney(s)*** under an **Enduring Power of Attorney*** to make healthcare decisions on your behalf, it is important to state what authority you have given your attorney(s) or **representative**.*
3. The final section is an emergency summary sheet containing important information. **Remove it from the rest of the form and store it in an easily accessible place for use in an emergency situation.**

We recommend that you speak to a healthcare professional before completing this section of the form as he or she may be the person best placed to give you the information you need when deciding about the care and treatment you would like.

2.1 Care Preferences Communication/Information

There may be some instances when your medical condition may prevent you from being involved in discussions about your health. You might be unconscious, or you might be conscious but unable to understand retain, use, weigh up the information needed to make a particular decision at a specific time or to communicate your wishes. With this in mind:

Would you like a relative, friend, or independent advocate to be present with you for conversations with the medical team, or at key events in your care?

Yes No

...
* See Glossary

?
Need Help?



Examples of Supported Decision-Making Initiatives

Irish

- Circles of Support. SDM Project for People with Intellectual Disabilities, Brothers of Charity, Clare, Genio
- Community Support Models for People with Dementia. HSE & Genio SDM Programme. Cork, Mayo, Tipperary, Dublin

International

- National Resource Centre for Supported Decision-Making
<http://www.supporteddecisionmaking.org/>
- Supported Decision-Making New York
<https://sdmny.hunter.cuny.edu/>



Thank you!

Further information
Email: fionamorrissey35@gmail.com