meaningful care matters

Toolbox Talk: Script

Mental Capacity and Decision making for people who live with dementia in a care home

A dilemma familiar to most care teams is how to enable choice v unwise decisions for someone who experiences dementia and lives in a care home.

According to the Human Rights Act 1998, a person living in a care home has the same rights as anyone else.

However, by definition, the fact that someone is in receipt of 24-hour care may mean they have less ability, physically and mentally, to manage their own care and decision making.

If self-care and decision making were possible the person would, in all probability, still be living at home.

So, what is the responsibility of care providers for ensuring the persons rights are upheld?

For this we look to the Care Standards Act 2014, The Mental Capacity Act (MCA) 2005 and the Human Rights Act 1998.

Specifically, in the case of decision making, the MCA provides direction about how we, care providers, must support someone who has impaired mental capacity.

The guidance is explained using five key principles which must be considered.

I will explain the five principles, using some scenarios, to help us understand how they should be considered.

This presentation is an overview and should help you with your work of supporting the day to day decisions for the people within your care.

Your manager will almost certainly have a copy of the Mental Capacity Act, Code of Practice which gives further helpful guidance.

Principle 1: **'A person must be assumed to have capacity unless it is established that he lacks capacity.' (section1(2)) p20**

This is our starting point.

Presuming capacity upholds the rights and dignity for everyone.

Dementia does not come in one size for everyone and we know that each person's dementia journey is their own.

Equally so is the capacity to make decisions. Let's consider this.

Scenario 1 - On Monday Mr X may be very happy to have moved into the care home and made the decision himself to remain there.

On Tuesday Mr X may be asking why he is here and demanding to go home.

Scenario 2 – Mrs Y may be temporarily unwell and struggling with the decisions of daily life.

She has a UTI and this has caused her to be confused about all sorts of decisions she usually manages very well.

We'll come back to Mr X and Mrs Y in a moment.

Principle 2: **'A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.' (section1(3)) p.22**

I am sure you have noticed the difficulty that some people have in making a decision.

Therefore, we must ensure that we do everything we can to help the person make their decision. What sort of things can we do? How can we make it easier for someone to make a decision?

Possibly, we can think about how we present the need for a decision.

Let's consider what practicable steps could have been taken in

Scenario 1 – Perhaps Mr X could have been asked about moving into a care home whilst sitting in the security of his own home.

For him his home probably represents safe familiar ground and may help him feel emotionally stronger and in control of his own life.

He could possibly have been invited for several decision-making visits before agreeing to move into the care home.

Perhaps he could have been helped to develop some friendships with other people living in the care home.

By joining the home for theatre trips, days out and parties or even just calling in for a cup of coffee.

It can be the case that people are admitted to a care home with very little preparation time. But even one or two short visits would provide an opportunity for the person to know something of what may be their new home.

A hasty admission immediately puts someone on a difficult starting point – adding further confusion, on top of that caused by their dementia, about what's going on. Many older people dread the idea of moving into a care home. It's often the one thing people say to their families that they never want to happen to them.

Sometimes it can be necessary to admit someone quickly and with insufficient preparation time. We rarely plan for a move into a care home in the same way that we plan other moves in our lives. Despite the reality that it is this move that can be so distressing for someone who already experiences disorientation to time and place as well as memory loss.

Perhaps you can try and think about how someone can be well supported when the possibility of care home life is presented to them.

What practicable steps could be made for Mrs Y?

Depending on what the decision is for Mrs Y perhaps it could wait until she was beginning to feel better.

Once she receives treatment for her UTI she may feel more able to make a decision.

There are many other practicable steps we can take which empower people to make decisions for themselves.

Our decision making is helped by feeling emotional strong, confident and in control.

We the care providers can help by speaking clearly using the right tone and pace for the person.

Meeting comfort needs: with a reassuring hug, a smile and familiarity that says we know one another, and you can trust me.

Ensuring hunger, thirst, and personal care needs are met, and the person is physically comfortable.

Being properly dressed, not needing the toilet.

All these things can put the person in the best possible position to make decisions.

Principle 3: **'A person is not to be treated as unable to make a decision merely because he makes an unwise decision.' (section 1(4)) p.24**

This principle can cause a great deal of conflict for the care provider.

Can you think of some of the unwise decisions you have seen people make?

There are many times during every day when people within your care may have made a decision which you consider to be unwise.

You may well have found yourself torn between allowing someone to exercise their right to make a choice about their care and your role to ensure their care needs are met.

Someone refusing medication and not accepting personal care are common situations within the care home.

Scenario 3 - Mrs A doesn't want to get out of bed today.

The care worker tries to understand the reasons behind Mrs A's choice but is unable to identify any specific reason.

She isn't sure Mrs A understands the benefits to her personal health of getting up, diet, movement, engaging with other people etc.

How to respond requires a great deal of thought.
After applying the above two principles the care worker must decide how to respond based on his or her knowledge of Mrs A. Her personal standards, her physical care needs, her current health and wellbeing status.

e.g. Mrs A is known to have a day in bed every so often – her nutrition, hydration and personal care needs are identified and recorded in her care plan along with guidance for how her care can be supported on the days she decides to stay in bed.

Mrs A hasn't had a staying in bed day yet this week and so today the care worker puts in place the `staying in bed' care plan, thus upholding Mrs. A's choice.

However, although the decision for an occasional day in bed is supported the care worker considers it to be an unwise decision. It's happening more frequently.

She believes that, whilst Mrs A remains in bed there are difficulties in ensuring all care needs are fully met.

- Mrs. A does not eat or drink as well when she is in bed – she keeps falling asleep during her meals.
  She has difficulty maintaining her weight and she needs to eat well to keep her weight up.
  Mrs. A can become dehydrated and she needs to drink the recommended level of fluids identified in her care plan which is good for her skin integrity, her bowel function, helping her medication to be fully absorbed and her overall wellbeing.

- The care worker knows that Mrs A's muscles are becoming weaker and she believes that each day of inactivity contributes to further loss of muscle. Becoming inactive means a greater reliance on mobility support (a wheelchair) which in turn reduces Mrs A's independence to walk about on her own and with other people, it increases her risk of falls, it means her skin integrity is at greater risk and she may develop pressure ulcers.

- The care worker knows that personal care, hygiene and skin integrity is not as well met when Mrs A remains in bed.
  As well as putting Mrs A at greater risk of developing pressure ulcers there is the loss of personal dignity by not being presentable to her usual standard – something that Mrs A was very particular about.

- Psychologically and emotionally the care worker knows that each day Mrs A remains in bed she is excluded from the socialisation, the daily goings on, in and around the rest of the Household.

- This in turn can mean her drifting ever further from reality.

- All of these things are bad news for Mrs A.

Whilst the care worker accepts that Mrs A enjoys the occasional day in bed and, on those days, her choice and decision making should be upheld, she also worries that staying in can easily become the norm.

The care worker discusses her concerns with her manager.

Principle 4: **'An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.' (section 1(5)) p.26**

Best interest decisions are made at complex and day to day levels.

For many people the need to live in a care home, surrounded by 24-hour care, is a decision so complex that the person who experiences dementia can find it difficult to make.

Best Interest decisions are made, following and subject to, a Mental Capacity Assessment, by a nominated group of people in the person's Best Interest.

The group can include people who know the person: a care worker, GP, Family member, Lasting Power of Attorney (LPA or EPA), an Independent Mental Capacity Advisor IMCA), Care home manager, anyone else who knows the person and ideally has been involved in their care.

Day to day decisions made with the person who has dementia require as much care and thought but less formality than complex decisions.

Whilst it is not necessary to conduct a formal mental capacity assessment for day to day decisions it is important to take steps `to reach a `**Reasonable belief'** that someone lacks capacity to make a particular decision' (p.62 MCA Code of Practice). It is also important to make a record of discussions and decisions made.

Another important factor to remember is that capacity to decide is decision specific.

So, whilst someone may lack the capacity in relation to one decision, they may not lack capacity to decide about something else.

E.g. being unable to make a decision about living in a care home doesn't mean someone is unable to make a decision about attending an activity or getting out of bed.

There are daily decisions to be made by every care worker in someone's best interest.

Some are more complicated than others.

Let's return to Scenario 3.

Mrs A doesn't want to get out of bed again today.

The care worker knows her well and assesses the decision.

The care worker is of the `reasonable belief' that Mrs A doesn't have the capacity to make a decision in her own best interest.

She believes that staying in bed occasionally is fine but staying in bed more frequently isn't good for her. The care worker also believes that Mrs A doesn't remember that she is staying in bed more frequently and also doesn't appreciate the detrimental affect this can have on her wellbeing.

She uses persuasion to encourage Mrs A from her bed: acting positively and enthusiastically with talk of the lovely things available today.

On some days, this approach is successful on others not but at least on those days she knows she has tried everything within her ability.

However, the care worker isn't at work every day and she wants to be sure that other care workers go through the same process each day and don't just accept Mrs A's refusal to get up without first trying to encourage her otherwise.

Her co-workers have also started to complain that she, the care worker, is refusing to respect Mrs A's choice to remain in bed.

Principle 5: **'Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.' (section 1(6)) p.27**

Let's stay with Mrs A - The care worker shares the situation with her manager.

Because there is conflict within the team the correct way to proceed now is to have a Best Interest discussion and include Mrs A's daughter.

It is important that a full discussion takes place and that the decisions are not simply based on one person's (in this case the care worker) point of view. We can assume that Mrs A will have a full health assessment from her GP.

As already said, it's also important, even with the day to day decisions that discussions and decisions are recorded in the care plan.

The care worker must be able to explain, describing how in her 'reasonable belief' she believes Mrs A's decision to remain in bed more frequently is not in her best interest.

During the meeting, the group must try to balance Mrs A's decisions to remain in bed against the risk associated with increased debility.

During the discussion they must consider all the reasons why Mrs A may be making her decision to remain in bed.

They must consider mental and physical wellbeing, including her main psychological needs: comfort, attachment, identity, inclusion and occupational needs.

Very importantly the group should decide whether or not Mrs A has the mental capacity to make an informed decision in this situation.

a) Does Mrs A understanding the potential implications on her health of staying in bed.
b) Does Mrs A need help to plan her day differently and, if so, what would be the least restrictive way of helping her?

This is a hypothetical scenario and whilst it is a familiar one, we cannot anticipate the outcome of this best interest discussion.

But thinking about principle 5 - What steps do you think could be taken to support Mrs A to receive the appropriate care? Care that she is happy with and that meets her physical and emotional wellbeing needs

Steps that would be least restrictive and acknowledge any possible health changes.

Some examples I thought of are:

- Perhaps suggesting to Mrs A that she gets up later, after a lay in.
- Perhaps providing her with her breakfast, while she is sitting cosy in her dressing gown in an armchair.
- Also helping her have any analgesics early on followed with a warm drink before she has to begin moving about too much.
- Returning a little later to help her get washed and dressed.
- Perhaps, if she does agree to get up at the normal time, she could be encouraged to have an afternoon nap on her bed which may help if she's feeling increasingly tired

Approaches to Mrs A and anyone else should be made whilst applying the person-centred care skills learned in Butterfly training. Knowledge of the person and their preferences and lifestyle choices is vitally important.

a) Knowing the person's life history and personal health needs
b) Knowing how the person usually begins their day; with the daily news whilst sitting with a hot drink, an early morning walk, talking to the cat, a cup of tea while washing and dressing…
c) Knowing the communication, familiar to the person, which motivates and encourages her/him of the opportunities available
d) Using music as a medium to lift the heart and spirit, singing a song, telling a story, a joke, talking of a memory.
e) Many care teams are very skilled and accomplished at encouraging and motivating someone – engaging with each person using knowledge of that individual.
f) Sharing your style of approach for these scenarios with your colleagues is a vital element of teamwork and benefits everyone.

Sometimes a person with dementia may make a decision that is not in their own best interest.

Whilst we endeavour to always uphold choice, we, the care providers, also have a responsibility to ensure people are supported well both physically and emotionally.

In the case of Mrs A and anyone like her, despite any best interest discussion to the contrary, it would be wrong to force someone to do something they don't want to do. That is not the purpose of this discussion.

This presentation is about how, using the Act, we can be sure that we've tried everything possible to help the person receive the best care that we can provide.

Physical care and emotional wellbeing go hand in hand.

They are both as important as one another.

But we neglect the person with dementia by simply accepting their choice when we know that we can do better by them.

Remember, ` reasonable belief'.

In Mrs A's case can you describe, with reasonably belief, that she is making her decision with knowledge of the effect on her health and wellbeing.

If you can that would demonstrate she has the capacity to make her decision.
It's an unwise decision that she is perfectly entitled to make; in the full knowledge that she understands the potentially debilitating impact of remaining in bed.

If you can't then you must make a decision in her best interest.

There are times when planning for poor decisions is difficult, e.g. when we may need to intervene in a situation that has compromised someone's safety or emotional wellbeing and possibly also that of other people, e.g.

- Someone is intent on walking into danger – perhaps crossing a busy road or into a crowd where they will become separated and lost from the care person.
- It's not uncommon for someone living with dementia to become disorientated and begin removing their clothes in public.

There is rarely time to plan for these events but once they have been experienced it's important that we discuss and plan for any future similar event.

I hope this presentation has given you an overview of the Mental Capacity Act and how by considering the Five principles you can best help the people you support.

Thanks so much for listening.

Mental Capacity Act Code of Practice
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

Human Rights Act
https://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Equality-and-human-rights/Older_People_Human_Rights__Expert_series_pro.pdf?dtrk=true

Care Act 2014
http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf