

Capacity – Carer Opinion

Carer opinion has been gathered from carer support meetings and discussions with individual carers, including those caring for individuals with mental illness, dementia, learning disability and autism.

We discussed these issues directly with:

- PASDA – parent carers of individuals with autism
- Glasgow Association of Mental Health Young Carers
- Bipolar support groups, Dundee and Edinburgh
- Edinburgh Carers Council AGM meeting
- Karen Alexander, MHO Lothian involved in a project on guardianship to help improve and streamline the process of individuals and families.
- Individuals who were carers and/or named persons for people with dementia and acute mental illness

What we found

Making decisions for someone else

There are two distinct camps on the subject of whether someone can take decisions for someone else.

Some carers were very clear that they felt this was necessary in certain circumstances. They felt that situations do arise where individuals are very ill with psychosis or mania, or have advanced dementia and are unable to decide what is in their best interests, and they certainly cannot be “persuaded” out of their opinions.

The fear of the alternative if detention was not an option was at the forefront of many minds.

Better “joint working” with the family and a commitment to listen to concerns expressed by family members earlier on in any potential relapse may allow discussion and supported decision making to take place before the situation becomes unmanageable.

Professionals all too often ignore warning signs flagged up by family which could prevent detention and the misery that ensues.

Conversations with trusted family or friends could help an individual early on in a relapse that could potentially be impossible if left to escalate.

Family relationships can be damaged due to periods of detention and any method to reduce the possibility of this happening would be welcomed

The difficulty is often accessing the services to allow this to happen

GPs and CPNs would need to be more aware of this as many emergency detentions will occur in the community. Involving A&E staff and the police in any training on these issues would also be beneficial.

Carers will be very willing to try de-escalation and discussion wherever possible, rather than have their loved one removed in handcuffs

There is a much smaller but strong opposing opinion, however, that under no circumstances should anyone be able to make a decision on behalf of someone else no matter who they are or how much they believe it is in the individual's best interests.

This body of opinion feels that deprivation of liberty should only occur if a crime has been committed and should be dealt with by the criminal justice service even if an individual is very unwell.

They feel substituted decision making is not justified merely to "prevent harm" and that these situations could be resolved by discussions with supportive family or friends.

They go so far as to suggest that forced treatment is no better than rape. They feel that more treatment options should be explored with patients and carers giving more options and therefore avoiding the need for detention.

There is not a clear option offered for individuals who are very unwell but have not committed a crime.

Decision making when there is a lack of capacity

On the subject of decision making when there is lack of capacity, again there are opposing views.

Many carers felt there was a definite need for this to happen where capacity was genuinely lacking, but many questioned the actual process of assessing capacity and therefore the right to make decisions based on this assessment.

Objections around the assessments include the notion that it is impossible to do properly with a patient, on a ward, out of their normal environment and surrounded by strangers.

Often individuals are in hospital for another reason like an infection which will further affect their "performance" and lead to an erroneous result.

Decisions being made by professionals who barely know the individual are criticised, and many feel these assessments should only ever be made with family input. A joint

approach would seem to be best as it is acknowledged that, on the other hand, family would not always be able to be objective

In this instance the idea of supported decision making could become a possibility if a familiar person was able to part of the discussion and might lead to different outcomes in capacity discussions. The language used and the surroundings are also very important and information on the person before they became unwell should be provided.

It is felt that lack of capacity should not be considered a fixed life term, and the notion of fluctuating capacity should also be considered. One carer described how a social worker presumed his mother had no capacity without meeting her because of her dementia diagnosis. In fact, his mum had Lewy Body dementia and retained capacity for longer than would perhaps have been expected. The social worker also declined to come and meet his mum to clarify the point.

This case also highlighted how difficult it is to assess capacity in a negative environment. The carer describes his mum as being very clear that she did not want to be in hospital and he felt she would have managed at home with increased support. On the ward she was upset and a bit confused and did not manage to do as well in an assessment as she could have done. She unfortunately was detained under the Mental Health Act as she was having hallucinations and he feels she “gave up” during her admission and stopped eating and drinking which led to her eventual death. Very distressing for all involved.

Lack of capacity should not be a blanket decision. Some carers felt that on certain issues, if their relative makes a reasonable decision that is in keeping with their previous wishes, then that should carry more weight even where there is doubt about capacity. It may be that they cannot manage their finances but are very clear on where they want to live. Individuals discharged from hospitals to care homes anecdotally do not settle as well as those admitted from home. Giving individuals the chance to try and manage at home with support is a much better and humane way to proceed.

Decisions should always be looked at individually and never taken by staff who have limited knowledge of the person. Some carers also pointed out that lack of capacity should not be presumed because an individual disagrees with a medical decision.

Treating people who do not want to be treated

Treating people who do not want to be treated is a difficult issue for many carers. Those with experience of relatives who have a mental illness tended to agree this is a “necessary evil”.

They feel that treatment is required to keep their relative safe when in times of crisis.

Others are totally against this view and feel that this is never acceptable. They suggest that as suicide attempts and manic spending or behaviour are not criminal offences; they are not reasons to treat someone against their will.

In addition, carers of older people with dementia commented that they are often rushed into decisions at diagnosis and feel pressurised to deciding about financial and legal matters too quickly. They can feel railroaded into guardianships which is not necessarily the least restrictive approach for some individuals.

The notion of graded guardianships may offer an alternative in these situations.

There is currently a project in Edinburgh where Mental Health Officers (MHOs) are working with families and solicitors from the time when a decision is made that guardianship is necessary. This is helping to speed up the process which runs alongside the search for a suitable placement and subsequently reduces delayed discharges. In this population a delayed discharge is not merely an inconvenience as it leads to a loss of function, skills, confidence and ultimately limits the options for discharge further.

Older people's carers did point out, however, that there is a point where communication and understanding is completely lost and they have to accept this.

They feel that better, more accessible information should be available for individuals with dementia and learning difficulties on supported decision making, power of attorney, guardianships etc., and of the consequences of these.

It was suggested that patients, especially older ones and their carers are generally unaware of advance statements and/or overwhelmed by the process.

Interestingly many carers who had power of attorney were not aware of capacity assessments being made.

A group of mothers with adult sons who all had autism and some also learning difficulties were unaware of any assessments being made despite the fact that they all had power of attorney in place.

Another interesting point that came out of discussions around power of attorney is what actually happens at the point where capacity is felt to be lacking and welfare powers begin.

Unless specified by the solicitor there is no monitoring of this process and it is unclear who decides this when it is decided and how.

Supported decision making

The process of supported decision making is being looked at very closely now with the recommendation from the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that substituted decision making is illegal.

This is alarming to many carers who feel for the safety of their loved one without the safeguards that they feel detention gives them.

Others, however, are in wholehearted agreement and feel that there will be no need for detention if a “trusted person” appointed by the individual supported them in making the “right” decision.

They feel medical staff should present the options to a patient and then withdraw from the process to allow the patient, along with their family support, to decide on the best course of action.

Interestingly this group do not have a clear answer on what to do with someone who is psychotic and a danger to himself, and others other than to involve the police if they commit a crime.

Others acknowledge that with the best will in the world their relative would not be able to understand and make a rational decision when they are in crisis and most agree that their relative would see it that way too.

Having an advance statement around these issues is very useful to everyone involved and promoting the idea of this is very important to give an idea of the wishes of a person who is so unwell they cannot voice them themselves

Intervention when a person has capacity

In terms of decisions around individuals who do have capacity but still want to die this was felt to be a “huge” question.

Some questioned whether the individuals had “true capacity” or whether they were still displaying signs of mental illness which would result in significantly impaired decision making abilities (SIDMA).

In this case, it was felt treatment may well improve their mood to a point where they felt differently. It may be difficult to refute this, however, without trying to treat and see what happens.

If an individual has lost sight of a meaningful recovery this must be addressed and time and effort reinvested into giving that person back some hope.

Unfortunately, the reality is that many people in these situations will not be detained and will go on to complete suicide if that is their wish.

Early intervention and listening to people could perhaps prevent some of these tragedies, and again this could be improved with greater value being placed on the opinion of family identifying that the person is becoming unwell.

Discussions and the formation of an advance statement when well will also be a useful guide when faced with such a dilemma.

Others feel any intervention is only acceptable if a crime has been committed and that individuals who wish to die should be allowed to do so in the same manner as those with a terminal illness can travel to use Dignitas.

Who can help with decisions when people are becoming ill and having trouble communicating decisions without being listened to?

Provision of support was felt to be most effective from a trusted relative or friend by most carers.

Support groups would provide too many conflicting opinions and was felt that they might confuse the issue rather than help the individual reach a decision.

A power of attorney or guardian would be a suitable choice for many as this is often a close friend or family member but solicitors were felt to be too removed from the situation.

The point was made that this should not be about people deciding what is in the patient's best interests but helping them make the decision for themselves. If they are unable to, then someone who can accurately speak for what the individual would have wanted if they could communicate it is ideal.