The views of people with lived experience on:

SUPPORTED DECISION MAKING AND PEOPLE WITH A MENTAL ILLNESS (draft)

some practicalities

JULY 2018

The following paper reflects the voice, experience and opinions that people with lived experience and carers, as individuals and as groups, provided for the Commission’s forthcoming work on supported decision making. It will inform our work and future reports on this subject but is not, in itself, an expression of the Commission’s views on this area.

Service user and carer groups may want to use the stories and opinions gathered, but are requested not to state that they are an expression of the Commission’s policy or opinion.

We are very grateful to all people with lived experience and their friends, relatives and/or carers who have contributed their experiences to this project. These are essential to the work we do and our philosophy of involvement and participation.
INTRODUCTION

In late 2017 and early 2018 the Engagement and Participation Officer (lived experience) at the Mental Welfare Commission had conversations with fifteen focus groups on supported decision making [for definition see appendix a] and how this might work in reality when people are acutely ill or distressed. He also had individual meetings and interviews with a number of people with lived experience.

The conversations involved 194 people in fifteen focus groups in:

- Wick – with Caithness Mental Health Support Group
- Thurso – with Caithness Mental Health Support Group
- Inverness – with HUG (action for mental health)
- Fort William – with HUG (action for mental health) and Support in Mind
- Aberdeen – with the Aberdeen Carers Support Group
- Dundee – with Bipolar Dundee
- Dundee - with Dundee SUN
- Perth – with PLUS Perth
- Edinburgh – with Bipolar Lothian
- Alloa – with Klaksun
- Bathgate – with West Lothian Involvement Group
- Glasgow - with Restart (Maryhill)
- Glasgow – with Restart (Bridegton)
- Glasgow – with Bipolar Glasgow
- Dumfries – with UCI and Kaleidoscope – Support in Mind

The vast majority of people involved were people with lived experience but a very small number of workers also participated as well as some carers.

We had previously had discussions with people with lived experience and carers on capacity, detention and supported decision making around a year ago; a report of which can be found on the Mental Welfare Commission website but wanted to follow up and find out from people just how and if people could make or be helped to make decisions when acutely ill and at risk of being treated against their will (substitute decision making)

The conversations resulted in three main themes:

- Whether people can make decisions when acutely ill and whether compulsory treatment is sometimes needed
- What can be done to support people to make decisions and participate in care when very ill and at risk of compulsory treatment
- What could avoid the need for compulsory treatment

During these months a number of people also spoke about how they felt services had changed for them to enable to them to live a life relatively free from detention and sometimes, hospitalisation, in contrast to the past where this was more common. Some of these accounts are included in appendix B.
Can people make decisions when acutely ill and is compulsory treatment sometimes needed?

Whilst we were not particularly looking for another debate about the pros and cons of compulsory treatment, this inevitably became a part of the conversation.

People spoke strongly in favour of the need for detention and substitute decision making in 14 of the focus groups with 49 comments recorded that compulsory treatment can be needed.

In four of the groups people were unanimous in saying that compulsory treatment is sometimes needed with some people being very indignant that anyone could consider otherwise.

- They are not the people who have been homeless as a result of this

People felt that there can be a need to intervene against a person’s will to keep them safe or other people safe, because their judgement can be so impaired that they cannot take some decisions for themselves. Some people who had been detained felt that there can be times when they are extremely ill, when they are completely incapable of making decisions and struggled to understand how supported decision making could occur at such times unless it was carried out in advance.

It was mentioned by some people that without compulsory treatment, some people would be likely to end up in prison and that with treatment more people would be able to live better and more dignified lives.

- When I was really psychotic – I was paranoid to the point that I wouldn’t speak to health professionals, I thought they were spying on me – I was very ill for ten years - then built up a world where my world did not mesh – I do not think any responsibility should be given to you at such times
- Without a doubt there are times when we need someone to take our decisions for us
- A friend called about me and I refused to let them in but they kicked the door down and took me to St Johns; in retrospect that needed to happen
- Having decisions taken for us can protect our dignity
- They would end up in prison – people can go on to recovery and live a good quality of life if they get treatment
- I think they were right to section me in hindsight
- If there was no compulsory treatment it would be chaotic - I would not like to be on a ward where there is no compulsory treatment
- You can need restrained for your own safety
- …but I need some security so I can’t get out of there.

When talking about substitute decision making and supported decision making four people in four groups said strongly they were against compulsory treatment and people in three groups said that despite being ill they can still often take decisions about their care and treatment and that often the opposite is assumed. It was also mentioned that being forced to do things against someone’s will can make them
angry and upset and, in contrast, being able to make their own decisions makes people feel better about themselves. All the groups mentioned the trauma and pain that detention can cause and ways in which this can be improved, especially to give people more say and autonomy than they presently have.

It was also mentioned that the treatment by and attitudes of staff can make it harder to make decisions and make it harder to be listened to: that not being able to make decisions was not always about illness or impaired judgement but about the way the system people found themselves in, responded to them.

One group wondered whether a person with a mental illness, especially if they have capacity, should be able to make a decision to die because the illness is so severe; saying that people with a physical illness can refuse treatment and hasten their death and therefore this might apply to people with a mental illness too. In another group it was stated by one person that anyone who is determined to die will do so whether detained or not. One person in one group believed that it was possible to provide community facilities which completely stop the need for hospital or detention and that such places have been demonstrated to work effectively.

- Even though I took the tablets and was up to high dose I could make decisions
- They should let you do things yourself and you would feel better in yourself
- If they give you more medication then you cannot speak and then they talk to you as if you are daft – some can understand and others can’t
- I don’t agree with this – I am against compulsory treatment
- In Italy there are communities where people just stay without restraint
What can be done to support people to make decisions and/or participate in care when very ill and at risk of compulsory treatment?

The approach and attitude staff take towards people in distress

People felt that one of the key ways of helping people take decisions when distressed and in avoiding compulsory treatment rests in the way staff approach people who are ill. Also their attitudes towards them can be crucial. This was raised in 13 groups.

10 groups said that sometimes the attitudes and automatic assumption of power and superiority by some staff made it difficult for people to want to engage or participate in treatment or decision making or for staff to pay attention to peoples wishes, this can occur in small acts or in their reaction to crisis which may traumatis people.

- When they keep typing when you are talking – show that they care about you
- I had five at my door and they said what is wrong and they look at you as if you are daft
- Often it comes down to attitudes – you are unwell and they don’t want to listen to you
- As soon as I got onto the ward I was chucked around by the nurses I shouldn’t have been chucked around by them
- A lot of people are suspicious if you are seen as mentally ill and cannot communicate with you because of this. This is a part of how you can be treated in hospital.
- On one to one – I was on this and – it got in a bad state and was shouting and raving five nurses got a hold of me and injected me – they should not have done that – they should have talked to me civilly

People wanted staff to recognise that people are likely to be scared and that they should be approached gently and with empathy and with a belief that, generally, people can make decisions about their care and treatment.

This fact, that people may not be able to make decisions in some areas but can in others and that this should be respected and expected was a strongly held belief by some people.

- When I was sectioned, I spent the first two weeks planning an appeal to the European court. I know there are exclusions for mental health. I had delusions that were needing treated but also there were those that need respected
- It was so painful and demeaning, they did need to keep me in hospital to keep me safe but my opinions on these were belittled and ignored. Some of my opinions were out there but no one talked to me about my delusions
- Just someone talking to me rather than someone brushing everything off
- Sometimes people say there is no point in speaking to us … they do not think you are in a state to talk

They wanted staff to know that compulsory treatment will be traumatic and that to help people engage they need to speak with them about what has happened. They
felt that key to helping people with decision making was: friendliness, good communication skills and an attempt to reduce power imbalances.

In addition staff need to explain what is happening and why and do the basics of asking people what they want instead of assuming they know what people need or that they will automatically understand what is being said to them. Combined with explaining what is happening is the need to create a humane and respectful environment.

- If they ask who you would like contacted for you that may be a start
- Treat you with dignity and respect
- Treat you like a person
- At such times I need a person who is gentle and who can reach through to me – they may get me talking by talking about things that are familiar with me - by being there with me – at other times someone who just gets it plain wrong can made me react and make me really angry – that gets me back into it too.
- Finland – staff eat with the patients and don’t wear uniform
- Get to the bit of them that is still in there- like make eye contact – be gentle, be friendly, show them that they don’t need to do it
- Without very good communication skills most people are at a loss to handle situations like this
- They need to believe you
- They need to keep calm: no shock horror
- I hated ward rounds with ten folk talking about you . They ask “Do you ken everyone?” And you don’t and they say who they are and you think …..Everyone has rights
- Being listened to and taken seriously

Two groups also raised situations where people seek help when in crisis or need to express themselves in certain ways and instead of being listened to they are dismissed and turned away. When people do not feel that their distress or need for help is being acknowledged then supported decision making cannot easily exist because people feel that their feelings and opinions are being ignored.

- I think it is bad; my friend was crying her eyes out but they just turned her away – they didn’t care – I have always been treated when I need it – they like to use judgement a lot but that can be subjective – for instance that suicidal threats are not serious

In contrast, some people made the point that when some staff do reach out and connect with them that the whole experience becomes better and decisions become easier to take and agree on.

- There is one nurse that really rang a bell with me. She said “I am your nurse for the day, I can see where you are just now and I will go away but I will definitely be back at 11.00” She explained the reasons. Some nurses say that and do not turn up when they say they will . She understood my condition
One group mentioned the need for staff to seek out the positives in people, with this approach, prospects can be better but so can attitudes and a sense of partnership and an ability to make decisions together.

- **What are your interests? Hobbies? Skills? Find all this out: what will keep people in their recovery journey?**

The more that staff are able to create an environment where people feel that they are on a shared journey rather than being told what to do, the more likely it is that decisions can be taken that suit the persons needs and desires.

- I don’t think there should be meetings about us without us in them
- I was in the CPA with my advocacy worker and they were talking about me and they didn’t let us in when they just called me in at the end.

One group also made the point that people with lived experience may have a responsibility to be open and honest with staff as well, in order that they can have an idea of how to treat them. Some people were also open about the fact that they do not get on with certain people and that accommodation may need to be made for this. Another group felt that certain professionals tended to treat them better than others and that this learning might be incorporated into training.

- It is hard to judge: a CPN doesn’t know what is on your mind and if you don’t tell her she will never know
- When you are so unwell you will revolt against them
- I can’t stand psychiatrists and yet I like psychologists – they have a lot of power but they do not ken you. The psychologist laughs and gets to know you. You can’t speak to psychiatrists naturally, especially if it is a man.
- Every time the police came when I was suicidal they were far better and respectful and human than half the nurses
- Are the police good because they have been trained? How can that apply to nurses in XXX? Could they learn from the police?

In summary, many groups felt that in order for people who are acutely ill to make decisions and participate in or control their care, staff need to approach them assuming that they can usually grasp what is happening and need to avoid doing those things that may cause patients to feel alienated or powerless or inferior. The more that staff can develop positive relationships with patients, the more inclined those patients will be to co-operate. It will also be easier for staff to find out how people are really thinking and what they actually want to do and have done to them. Supportive decision making may be as simple as introducing humanity and calm into fraught situations.

**Stating in advance how people would like to be treated, when at risk of compulsory treatment**

When looking at how people can take decisions and have their views taken into account when acutely unwell and at risk of compulsory treatment, seven groups mentioned the value of making advance statements. However one group while saying that advance statements were a good idea also had doubts about their value; both in people being able to access them and in them being adhered to.
• Check for advance statements and that they are up to date and at the front of your files. They can’t find them: this happens a lot
• Last admission they printed all my information and about the side effects. They gave me the choice of whether I took it or not and this was in my advance statement.

One group said that having a crisis card saying what to do and who to contact in an emergency could be helpful as would a buddy card.

The existence of patient passports and powers of attorney were also raised as valuable ways of helping with decisions at these times.

A trusted person

Eleven groups said that one of the key ways of being helped to make decisions is to have a trusted person who knows them well and who can both assist them to make decisions because of the relationship that they have with them and because they have a good understanding of their wishes, needs and experiences. Groups also felt that some staff were good at creating a sense of trust even when the person being treated was not well known and that this was very important.

A variety of people were mentioned who would fit into this category. It could be a friend or family member or it could be a professional such as a CPN.

In one group, comment was made that it might be better to have someone who is not in a person’s very close social circle or who knows them best to take on this role, presumably because there may be elements of that personal dynamic that could be damaging when trying to ascertain someone’s wishes and to help them to make decisions.

Another group said that some people do not have anyone in their life who could fulfil this role.

It was also mentioned that if a worker knows you well they will have a far better idea about whether to intervene or not compared to a worker who has little or no knowledge of the person.

• I can only think we really need to know someone really well then if something goes wrong then you know what their wishes are
• Key is a trusted person
• A personal experience: I was taken in to hospital, I had an advance statement. I was delusional and very scared and my friend came in and brought us in and spoke to them about it and said ‘This is how XXXX would normally be’—she was asking me and reminding me
• You will be phoning Inverness and have to explain to them, they will contact Wick. The local ambulance know ‘Jimmy’ and they will get to ‘Jimmy’ because they damn well knew him and knew he needed help in a way the city people don’t
• It is about trust. I wouldn’t trust my family but I would trust my psychiatrist
• I will not talk to someone I don’t know: I cannot open up
• I can push close ones away and can feel family and friends are better off without me. So having someone that knows you and doesn’t talk down to you and have real empathy is important
**Named persons**

Four groups mentioned the importance of named persons; both to help people make decisions and to calm down the situation but also to act as a voice for the person they are a named person for, although that is closer to the role of an advocate than a named person.

In a development of the role of named person, one group suggested that a named person could take decisions on behalf of the person when they were unable to themselves, bringing the role closer to one of Power of Attorney as is found in adults with incapacity legislation.

- *I would like to say in as that if I am unwell and can't make decisions that they should let my named person take decisions*
- *Maybe when you do your advanced statement; do it with your named person so that when you are in a crisis they are aware of what will happen to you and you can trust them. Maybe they should sign it too.*

**Dignity**

One group highlighted the need to be respectful of people, even if they appear to be out of touch with reality, and said that this constant awareness is vital to ensuring people are treated with dignity, again this approach is likely to make it easier for people to participate and be encouraged to participate. This theme could also be seen throughout the thoughts people had on how staff should approach and think about the people they are caring for.

- *We can lose capacity; it needs to be formally assessed – my mother used to be a nurse and nurse patients in a coma or nonsensical state but they always said you never know what someone can understand or hear – they could transfer this need for dignity to us.*

**Information**

When trying to make decisions, five groups said that it was important that people were given the information that they needed about their condition and what was being done to them. If this was done, people would be more likely to participate and more likely to be able to make decisions. People will always struggle to make decisions if they do not know about their diagnosis or how they are being treated or are expected to behave.

- *Maybe if they came with knowledgeable stuff about your condition to inspire you to have confidence in them*
- *It wasn’t till I said I am going home in the middle of the night that I found I was sectioned. I wasn’t at all happy I was trying to phone my kids to come and pick me up.*
- *When I was depressed no one told me I was on suicide watch*
- *Remember you will forget*
• They should tell you the side effects of your tablets
• I got wrongly diagnosed at first with schizophrenia and was re diagnosed with bipolar and everything fell into place
• I am diagnosed bipolar and understand but then they diagnosed me with e.u.p.d. too. I thought it was schizophrenia; I said “Can you write it down?” They just gave it me and threw it across the table at me and did not explain that I had both. I was so scared.
• In hospital explain why and give reasons; don’t just say “We will be doing this”. I didn’t even know I wasn’t allowed off the ward

Two groups said that if people work together, maybe to the extent of creating joint care plans that patients also have copies of, then, decisions are far more likely to meet a person’s wishes and the person is more likely to be able to take those decisions.

• Write it down and keep it in your room to let you know what is happening
• Have a Care Plan that you know and agree to
• Tell you what they have written about you; don’t keep their knowledge to themselves

When giving people information, people feel that it is important to remember that in order for people to use it, to make sense of and take decisions about their care that they understand what is told to them. It needs to be provided in a way that they understand, which means looking at access issues.

• I cannot read properly; they should explain it to you

When giving information one group said it is also important to let people know about the range of services and supports that are available rather than just about hospital or community services. If people know what exists then they can both make decisions and possibly also access help that prevents them getting to the point where they may lose capacity.

• Simply letting people know what is out there: that if people know about it they will be sent by XXX and that is part of the signposting. It would make a huge difference.

Advocacy

One group mentioned the value of being able to access advocacy when trying to come to decisions about their care and treatment.

• You can use advocacy

THE HOSPITAL ENVIRONMENT.

The way a hospital works and functions and is built has a major impact on how people feel about themselves and therefore if they feel able or willing to take part in treatment or decisions about their care.

One group raised issues about a lack of activity and also the promise of activity that didn’t happen as a reason that people can become disillusioned with treatment and another highlighted how difficult ward rounds can be and yet felt that with some
accommodation these could become experiences people maybe benefited from rather than dreading.

- In XXX they put up ward activities every week but not once do the activities happen – the ward staff never did anything
- Standing in that queue to get fed: it was like feeding time at the zoo
- You can need to be able to make phone calls but often you cannot use it or afford it. I was in hospital without adequate clothing or money
- In a ward round. Let you have a cigarette to help calm your nerves or a drink or food to help you calm down. With 8 nurses you can feel you can’t speak. Before and after. Medication can help to calm you down or a nurse you get on with or a friend from the ward.

In many ways the suggestions made in these sections reveal that when we are talking about helping people have as much of a say as they can have in their lives and the care they are being given, when at risk of detention, then much of the ideas boil down to simple and basic ways of treating people:

Find out what they want, in advance ideally; develop a good relationship, find people who have a good knowledge of them and what they would want or not want done to them. Involve trusted people when it looks like decisions are likely to be taken out of their hands. And assume, as far as possible, that people will at least be able to make some decisions, so give them information in a fashion that they understand and treat them in such a way that they have the confidence to participate and the faith that as far as they can, that the people caring for them will try to respond to the majority of the wishes and needs that they have and where it seems like they are at risk of not being heard, involve advocacy.

What could avoid the need for Compulsory treatment?

These focus groups were all about finding out how people can (and if they can) make decisions when they are acutely ill, and possibly so ill that decisions are likely to be taken out of their hands.

However most groups also wanted to point out that key to supported decision making is the sort of systems change to health services that means that people do not routinely get so ill or distressed that compulsory treatment is a common option
for them. People would be able to take decisions and to participate in their care if they have access to the sort of help that means that they do not end up critically ill and where their judgement is so impaired that they can no longer grasp some of the world’s basic realities.

**Getting help before the crisis gets too bad**

When looking at supported and substitute decision making, five groups were keen to point out that if services could help earlier, when people were approaching crisis, then many people would not get to the point where compulsory treatment and substitute decision making was becoming a likely option. They also pointed out that crisis plans and relapse plans could all play a part in supported decision making and in reducing the likely hood of compulsory treatment being needed.

- **Last time I was in hospital I was down at A&E, the duty doctor went home then the police came, I was paranoid – I got some swords that were telling me to stab them – next there were hundreds of police – (we [the group] all agree that at these times they should have intervened) - but they should have helped before hand**

**Prevention**

Two groups said that if services could intervene early in the development of a person’s illness then the chances of it progressing to the point that compulsory treatment becomes likely will be diminished. Making the likelihood of people developing mental health problems in society less, would, for them, be better than having to deal with the end results of mental illness.

- **If there was early intervention and help before it escalated, maybe we wouldn’t need to have sectioning – if they could pick up on it in teenage years where it often manifests**
- **Our GP’s could have a role in prevention with more mental illness training and knowledge of who to refer people to.**

**Safe places and protection**

Five groups talked about the need to give people a sense of safety and a safe place to go in crisis, feeling that if they can go to somewhere where they feel safe and looked after, that they are less likely to get into a position where compulsory treatment is needed.

One group said that there are some people for whom there is a need for a protected and safe place in which to live. They felt that some people will never integrate into the community and never be truly in a position to manage. They felt such people may need specialist facilities in which to live and be cared for and some wished that they could have access to such a place.

- **I need to be kept safe and taken to a place of safety at such times – I need looked after**
- **Some people cannot make the step forward: they need a village where they can be looked after and where those that cannot mix can be ok**
- **Take you somewhere where you are comfortable and at ease**
We should go to community units and supported accommodation – back to how it used to be
I think most people would like to be in supported accommodation not on their own
You need a buffer between admission and crisis: a safe place to go that may avoid escalation; a sort of safe-house with people qualified to understand and listen
There have been a few times when I have just needed a couple of weeks out to avoid longer admissions.
People who are distressed and suicidal have presented repeatedly to XXX and have not been able to be admitted and have committed suicide because we had no safe place. We need somewhere with beds
Hospital is not always the right place: a place with some beds and things to access: people to talk to, links to a phone line and someone to speak to on the phone who can keep you safe.
Cabins with a sanctuary; by a waterfall with healthy living and therapy and rest and things to do: a place of peace and silence.
Maybe more phone line support but more professional than the Samaritans - if I am having a crisis I can talk it over; I will phone up my mum or sister but if I was wanting something clinical, I would phone up someone medically trained

Lack of services and support
Nine groups said that if we are to avoid compulsory treatment then we need to have adequate community and hospital services in order that people can get the support and care they have a right to.

They highlighted examples of continuing cuts in services and support and felt that this led to extreme situations that could have been avoided from developing.

The number of times when people have not been looked after and probably not got the right medication and ended up committing murders
They have shut down a lot of hostels for men – people died
The way the NHS is, you don't get a bed unless you are really ill
Last year neighbours phoned the police 9 times and the person died – the police do not respond even though you are a vulnerable person
I was in a situation where there were two people in crisis here who were on their books and they said “Phone the police.”
Intensive home treatment also sounds great for that but we do not have that
If I hadn’t been known to services – I would not have got help – that bothers me.
I needed help when I was at home on all this medication; the psychiatrist said ‘We do not have enough CPNs in the team’ – I have no one to treat me.
We need access to services in first place – such as a psychologist
Say you have an older person with a mental illness who lives with his family and for some reason his family don't look after the chap and he gets suicidal; life is not liveable. Does that guy need hospital or need taken out the situation he is in? How do we do that? –we need a place and people that can deal with the social issues that are making people suicidal.
Have things to keep you busy
I have been more or less on my own all the way through and no one comes and no speaks. I could take myself out at any time. It is not as easy as that. My place is filled
with staff helping staff and not one of them comes near you, or asks round the door or asks if you are feeling good

- Peer support: suicide survivors who can help other people; then you would be more likely to phone someone
- In Yorkshire one farmer said “I will start by phoning other farmers and saying ‘Are you all right?’”

Self Management

One group felt that another important way of getting to the point of making decisions and avoiding detention rested in the need to have a thorough personal understanding of yourself, your experience and your condition. From this a greater degree of autonomy could be exercised.

  - With this illness we need to look deep inside ourselves and see if we can control ourselves and for your own benefit keep ourselves quiet; you need to hang on to you but this is very difficult, but I have managed to stand still and stop my nonsense
  - It is about having coping strategies

Alternative approaches

One group suggested a couple of ways of dealing with distress that they felt may reduce the likelihood of distress and mental ill health and therefore the necessity to detain people. These approaches were both about challenging the medical model of treatment and seeing if there were other more effective and humane ways of dealing with distress.

- We need a range of natural medication – if I look back at almost every breakdown there has been some mistake with my medication – there may be a place for drugs but a natural approach can help.
- The medics go on the medical model and are constrained by it. It is too easy to say drug someone. Let them sleep, talk to them and give them a safe space but not necessarily in that order.

CONCLUSION

It is clear from these conversations that the majority of people we talked with believe that compulsory treatment and therefore substitute decision making will sometimes be needed but it is also clear from this and other conversations at these meetings that compulsory treatment can be traumatic and damaging and should be avoided where at all possible.

Some people, when asked about whether they can still make key decisions when acutely ill, strongly believe that there are times when they cannot make any decisions and should not be put in a position where the asked to do so.

However most people felt that there are many points, even when in extreme crisis, that people can make decisions and should be supported to do so. A key element of being helped to make decisions is the basic good practice people would expect from
psychiatric staff in how they approach them and relate to them when they are very ill or distressed, which at its simplest appears to be being approached in a respectful, gentle and compassionate manner.

Apart from this, people felt that a key element of being able to make decisions or to have decisions made in accord with their wishes is to have a trusted person present ideally who already knows them well or to have trust in the staff providing treatment.

In addition the support a named person can provide and the evidence that can be provided by advance statements, crisis plans and patient passports and power of attorney can all assist in supported decision making.

People in the groups we met were keen to add that they felt that some compulsory treatment was a direct result of a shortage of services, a lack of preventative help, early intervention and safe places to be treated in and live in. Supported decision making would be more likely to be the norm if people were given enough help and support to make crisis and acute illness less likely in the first place.

People felt that if services did not appear to be geared towards just treating people when they can no longer cope but provided the sort of support that meant that people had a better chance of maintaining good mental health, then the need for substitute decision making would decrease and people would routinely be able to make decisions for themselves with or without support to do so.
Appendices

Appendix A

Definition of supported decision making from MWC Good practice guide – supported decision making.

‘What is supported decision making

Supported decision making has no formal definition and different people use it differently. We use it to refer to a process in which any individual is provided with as much support as they need in order for them to be able to

1. Make a decision for themselves and/or
2. Express their will and preferences in the context of substitute decision making (for example Guardianship or compulsory treatment for mental disorder)

In both cases the purpose of supported decision making is to ensure that the individual's will and preferences are central to and fully respected with decisions that concern them.

Substitute decision for an adult should only happen where there is specific legal authority. The main pieces of legislation that authorise substitute decision making in Scotland are

- The Adults with Incapacity Act which provides for guardians and attorneys and sets out procedures to authorise medical treatment where a person lacks decision making capacity
- The Mental Health Act which allows for detention and treatment linked to significantly impaired decision making ability
- The Adult Support and Protection Act which allows for short term intervention for ‘adults at risk’

Note from the author: Another simpler way of looking at it is that a person who is sectioned or detained will be made to accept the decisions of another person about how they are treated – this is substitute decision making.

A person who is helped to come to their own decisions about treatment and is not detained or sectioned and has their decisions respected is experiencing supported decision making.

If someone is detained and their views are still listened to and respected then an element of supported decision making exists.
Appendix B

Personal experiences and views

Ms M

Making decisions when unwell

I have some experience of making decisions about my life in general when very unwell, usually in hospital, and will never forget my dad telling me that I should never make any important decisions while in the hospital.

I always have lots of ideas and make lots of decisions while I'm unwell but often change my mind once or twice by the time I'm home.

It's very confusing at times, (which may be partly due to high dose of antipsychotics)

I don’t always feel able to make decisions about my care and treatment when I am ill and in hospital but I am happy that my Advance Statement is strong enough in these circumstances.

In the past have had trust in the people mentioned in my advance statement. Sadly that wasn't the case due to a breakdown in family relationships when I was in hospital last October but luckily a couple of my close friends stepped in and helped sort this out.

I'll now be updating my Advance Statement as soon as possible – it is important to remember that our wishes can change rapidly as circumstances change as can the people we would like to help us speak out or help with our care.

I sometimes struggle with decisions when I get home due to lack of confidence in my ideas. It can also feel very patronising when family, friends or members of staff question my decisions when home.

My WRAP Crisis Plan is also pretty clear about how people can help and what the signs are that I need less help in order to take back control and move forward.

I try to update my Crisis Plan at the same time as my Advance Statement i.e. post crisis and keep a copy of it attached to my statement. However even when I am very organised and take notes about my care after a crisis. Actually updating my advance statement or crisis plan can take some months to do, it is not the first thing you seek to do when you are recovering again, sometimes we can go through a great deal in our personal life during a crisis and it can take a long time to process this.

At some points we can make decisions with confidence and can find ourselves put out when people question this and at others we can be too ill to make decisions and need other people to either take them for us or help people to understand what we would have liked to have happened if we are well. It can be hard to keep the balance right so that people are clear about when we need and have every right to the
decisions we take and those times when we need people to take some degree of control for a while.

Ms J

Avoiding the need for detention, being in control of your own life choices

I can make decisions for myself nowadays and know when I am ill and need to stop doing various things. This needs to be respected, however I can imagine that there are people who get in a space where they are no longer able to make decisions. Sometimes it can be necessary to section some people, but it can be done unnecessarily and has caused me incredible damage in the past.

One of the major flaws in the system is that we can be sectioned and because of this can worry hugely about if we will be sectioned and when we might be released from it.

In fact sectioning is always traumatic and people who have been sectioned because of severe mental illness have also nearly always been traumatised in the past. There is a need to deal with the inevitable re trauma that sectioning also causes people.

I feel that the way I am treated nowadays has avoided the need for me to be sectioned, largely down to the way in which my psychiatrist has worked with me, who has managed to challenge the opinions of other colleagues who have felt that I have needed sectioned on occasion over the last few years.

I feel that practitioners need to be aware of the ‘nocebo effect‘. We all know about the placebo effect but when doctors or other care givers hold negative ideas about us or our prognosis it can have a very powerful and deleterious effect. People will live up or down to expectations quite often and it is up to everybody to hold the highest degree of hope and positivity about a patient's ability to heal. This is particularly important when people have been through the trauma of having their rights removed and being detained against their will.

I take my medication on a PRN basis when I feel I need it and have worked for many years with a consultant psychiatrist. He knows me well and has established a good relationship which has enough boundaries to make me feel safe. He is non-judgemental and not sexist which is important to me. He is happy to live with a degree of risk that other people have tended not to be. He has also agreed with me that some of the ways I have been treated in the past by psychiatry have been abusive, which is important to me. I have managed to remain free of being sectioned for many years due to this approach but there have been times when it has been close; there was one time when I was high and out on pass and was wanting to go to the school my son goes to and my son was worried about the impact that would have. At that point he told me that if I walked into the school then he would have no choice but to section me and this was enough to stop me.
My GP is such that if I phone the surgery and say I need to see him, that he will usually do so within a couple of hours and can often be found even if it is his day off. He knows I don’t take advantage of the flexible way in which they deliver care and that when I need to see him I really do need to see him. He agrees with me that medication is not a solution in itself and that there are other roots to these issues. He has what would once have been called an ‘old fashioned bed side manner’. He is straight talking and quite outspoken and at the moment is trying to find a CPN for me but wants to find one that he knows I will be comfortable working with.

Key to avoiding times when I would probably have been sectioned is the relationship that I have had with my psychiatrist and GP who are both experienced and have known me for many years.

My psychiatrist is great, he is fantastic but there is a danger that because I get on with him so well that I will buy into the medical model more than I should because I like him so much so it is maybe good that I am due to see a different one soon. For me; I am on a quest to understand and am more in interested in people who beat the odds and how they do it. I will still continue with hypnotherapy and am happy that the doctors give me the benefit of the doubt, without that I would often have been sectioned.

It sounds almost wrong to say this but I feel that my doctors love me and feel compassion and respect for me but do not breach any boundaries that could make me feel objectified or threatened.

I need a person who is strong in themselves: my psychiatrist will share aspects of his life with me and show his reaction if I surprise him with some of my experiences but he is bombproof. I never have to worry that what I say or do might harm him.

My doctor is a good and strong man who respects boundaries so he may shake my hand when we meet but he will not ask me out for a coffee. He is happy to say that I am articulate and intelligent and has said I am more intelligent than him but he is not at all threatened by this. It is very important, especially for women, to feel safe with the people treating them.

A couple of examples about attitudes:

I was high and in need of a hospital bed but they were insisting on unnecessary assessments and procedures which were really upsetting, when all I wanted to know is that there would be a bed available for me. The nurse who was dealing with me was unpleasant and authoritarian. Eventually I demanded to see a doctor; he listened to me when I asked to be given a specific nurse as my key nurse, who had been very good in the past, instead of this nurse. He said that he would try to make this happen but in return he wanted me to agree to try to work with the nurses and to work to get better. I agreed. The new nurse was amazing and did the first ever cost benefit analysis of my bipolar and helped create the first proper care plan for me that I had seen. He was very dignified and approachable.

I have had suicidal depression recently and have been unable to ask for help or express how I was feeling. When I told my doctor that I was bad and needed to die
he told me to that the impression he had of me as a person over the years was nothing like that. It made a great difference. The same happened with a hypnotherapist that I went to who worked on my conscious and unconscious to redirect my belief that I was responsible for my sister’s death and that my family wanted me dead. He helped me see that these beliefs were not based in fact which was a huge relief.

We can know that we are bad and need to die and at the same time know that we are also good people.

There was a time when they decided to use acuphase on me; which I was very resistant to. To my mind giving that against someone’s will is like a form of legally sanctioned assault by the state. However there was an admission some time ago when I was deciding if I wanted acuphase and one moment would say I did and the next that I didn’t. The nurse who was with me was patient and kind while I tried to decide about it and in the end said she was very glad when I said I wanted it.

There have been nurses who have been loving and kind and respectful and others who seem to take a pleasure out of winding me up and bullying me when I am in hospital.

Sometimes it is seemingly small things, like one time when I was, at last, managing to relax in a relaxation class in the hospital and a nurse burst loudly into the room and ordered me back to the ward unnecessarily and in a very unpleasant fashion. Or another time when I wanted to go out on pass and some of the nurses who knew the father of my son said “What about him, if she goes on pass?” And yet my psychiatrist had enough faith in me and my level of illness to say I had every right to go on pass and that if my relationship with him was unhealthy and involved domestic abuse that was an area of my life where I had a right to make choices and had little to do with illness.

Mrs H

Impaired decision making and supported decision making

Impaired decision making is when you have poor mental health so that your usual reasoning cognition, concentration and decision making is impaired, so you don’t, if you like; hear, you don’t comprehend the information given to you verbally. You may misinterpret something that is written down which when you are well you would have no problems with whatsoever.

In my case it could be when I am severely depressed; I hate answering phone calls, I wouldn’t make phone calls, there is a feeling of deadness; it is total disconnectedness. You don’t assimilate anything and therefore you are not acting on anything to improve your health; you do not seek out help.
The first time I was actually in hospital I couldn’t understand how someone who was well educated could not cope with everyday tasks, I could not say I wanted tea not coffee and if it came to any more significant decision I couldn’t do it.

I would leave all decisions about everything such as money to my husband. I wouldn’t ask any questions because I was not able to articulate or ask for information; it was total passiveness. I probably needed people to make decisions for me. I felt like I needed to be in hospital.

I recognised that the depression was coming on and went to the GP and said I was getting ill again and was prescribed medication that I was told would work better than what I had been prescribed before. From what I now know it probably made me more suicidal than I had ever been in the past. I didn’t really know the GP and her understanding of mental illness was not particularly good. Within a fortnight I took an overdose so I was taken to the local hospital.

I think it was spur of the moment. It was an overwhelming feeling of not coping and not wanting to be around, it was about dramatically going downhill which was not like subsequent depressions. I just didn’t want to be in the present, I had all the lethargy and was hardly eating, I wasn’t interested in things, I don’t think the overdose was life threatening but I also don’t think it was a cry for help. I know my husband needed help and got the nurse straight away. I can’t remember the journey to hospital, I needed someone to intervene. I don’t think my husband even knew I was suicidal, it was quite weird.

At that time I am not sure if anything could have been done to help me make decisions. I remember at that time just staring at the water when with friends; nothing made sense but because I was with them there was not the possibility for me to act on how I was feeling. It would have needed a skilled person to pick up on subtle signs from me that I was this ill; my husband was used to me being apathetic and not doing things and probably couldn’t see how ill I really was.

What I would like now is someone who had been trained to discuss how I was feeling at the time, my thoughts about what I want to happen and if that comes to a negative answer because you can’t see past the next hour; to have a meaningful conversation that talks about hope, not to avoid the idea of suicide but to explore that with you and spend time with you, it needs someone who doesn’t need to be going off to someone else for their next appointment. You need to be the important person that they are trying to communicate with and help and you need to know this. You need to be able to trust them and gain their confidence and to be able to give them permission to talk to other people who might be able to help you until hopefully you get through it. They need to communicate with the most appropriate skilled professionals about how to take things forward.

It’s never going to be possible to get the suicide rate to zero if someone is acutely ill. If there is a high chance of being able to recover then whoever is able to help should do so for humanities sake; to help keep that person alive and hopefully with or, in desperation, without their permission, to summon help to get them somewhere safe.
There is the balance between being acutely ill and wanting to die and having compulsory treatment; which seems right and proper and wanting to die and having an illness but also having capacity. An assessment of someone’s life can show that they do not see the way they live as acceptable and in this case when they have capacity they should be able to choose to die.

With the first one where someone has the chance of recovery to an acceptable standard, then intervention should occur even where they are not happy about it but if, ten years later, that same person has judged that their life is absolutely awful: a sort of ‘I have been through this so many times, I no longer want medication and want to be left to die.’ But how do you know if someone has the capacity to say this? It is not an either or thing, but sometimes it might be unreasonable for people to go through the pain again and again and again.

It can be very blurred; personally I do have faith in clinicians being able to make some decision as to someone’s mental state. They will not always get it right but I would worry if they were not able to make a fairly accurate judgement of a person’s capacity and illness.

However even when you are severely ill you can make some decisions; there are certain things such as food that you can decide on, you still have capacity for this. But to try to define capacity; you have so many aspects such as language and communication and education. Even when people are very ill they will use certain words because of their education that can lead to some people thinking they are less ill than they are.

How do you assess someone’s capacity? You need to know them when they are well too, to know what they can normally do and to be able to compare it to how they are now.

The thing that comes to me is I would still find it difficult to ask for help. I have my letters that I have left with trusted people to contact my psychiatrist if they think I am ill and need help as I do not seek help when I am ill. But how does someone who is isolated manage? What happens to them? They will not set up a therapeutic relationship. Who will be in a position to say they have capacity or not if they do not already know them.

When I went high I was spending money I shouldn’t have. I think the bank stepped in or my husband did, thankfully it didn’t get too out of hand.

I kept walking past the door of CAB; I went in and spoke to them about benefits; we had no income. If they hadn’t been there I would not have phoned them later. When you are making decisions you need the people who can assist you, who have a good reputation and who you have confidence in, to actually be available.

I was just putting my self assessment tax form in the drawer and eventually they got social work involved and they wrote to the HMRC to say I was too ill to do it and months later, when I was a bit better I got the confidence to phone them. I had thought I owed them mega money and that I was going to prison. My decision making was badly impaired; I was too ill, too proud, too frightened but when I bit the
bullet I found out they owed me money instead and here was a really helpful person on the phone who had the letter from social work that said I was ill and that they would sort it out.

There should be a failsafe for people who spend all their money when they are high; ideally when people are well they would set up power of attorney for when you cannot make basic decisions when you are unwell or an arrangement with the bank not to loan people money when they are unwell. I don’t see why banks couldn’t be educated enough to recognise that this situation can happen: to try to put a stop on an account if someone’s spending follows an abnormal trend, especially if you have told them in advance of illness.

But you still need to pay your bills and food, how do we deal with this? Ideally they would be able to say this person is too ill to pay their normal outgoings and therefore it has to be put on hold but how this is resolved a bit later when they are more stable and need control again: how does it go back to normal?

It shouldn’t be the case that people lose out financially because they are ill. There should be someone who can help with your account and money in these situations.

Advocacy is, to me, vital for assisting people to express themselves and make decisions, they have training and skills in terms of listening to what the person is saying and trying to understand, from the persons point of view, what they are saying and trying to help the person communicate their views and opinions. Because advocacy is independent the individual might trust them more. They listen to the person but can't make decisions over the person. There is not a power imbalance because they cannot agree to a decision on the person’s behalf.

It shouldn’t be just about compulsory treatment. It is often obvious that a person needs treated and is ultimately glad that they are alive even if they did not agree with the section at the time. It is about being involved in drawing up your care plan or your anticipatory care plan. You need people to get to know you as a person. If you are able to express your usual interests and likes when you are well, for people to know about you as a person and the things you would like them to know. One way is an advance statement and a personal statement: the detail that you think would matter to someone who doesn’t even know you, like how to be treated in an emergency. It needs easily accessed.

You need someone who knows you well and knows what you are like as a person and what you do and don’t want to happen to you. People like this could be contacted to get information about you or to ask what makes you tick or how to approach you and things like that; almost multiple named persons.

What worries me is; all the professionals who know me are retiring. They have very good knowledge of me as a person and of my treatment and would know what works for me and what I do and don’t want to happen.

I think most of the time I have been lucky, my views have been respected. Even when I was detained: There was a time when I did not want a certain medication and that was agreed with. The psychiatrist and pharmacist knew my views about the
medication and abided by them even thorough ultimately they were right and I was wrong in the choice of medication; they let me try it my way to start with. Because I was known to staff in the hospital before I was admitted, I think they found it easier to see me as a person with valid views and wishes than if I had just been a stranger coming in as high as a kite.

I am just amazed at how patient my psychiatrist was and the amount of time he gave me to listen to my opinions and wishes about my treatment.

Trying to define capacity is so difficult, I have looked at my writing from that time and clearly was very ill and did not have capacity in many areas of my life but in other areas I clearly did have capacity and this was also accepted. I could make suggestions about when I got my medication in order that I could do certain activities and have this agreed to.

But I did not have control. I have never been so angry in all my life at being told what to do, but my mind was illogical, impractical, unrealistic. Some part of me knew some of the things I wanted to do were impractical and stupid and shouldn’t happen and I had no idea how awful I was at phoning people at all hours of the day and night or of the demands that I was making on friends that I should never have made.

Looking back I am sure I was psychotic; it was real but not real. I had a thing about Nelson Mandela and wanted to go to South Africa for his birthday party and thought a stranger on the ward was really famous; things like that, but I could still make all sorts of decisions including some about my treatment.

In some ways it is just obvious: most people nearly always know which areas we do not have capacity in when we are very ill but in order to find this out properly they need to talk to us and be with us and listen to us and find out about our world is like.

MS S

Supported Decision Making and People with a Mental Illness

• Supported decision making –

Could there have been ways of approaching and involving you that would have (1) given you more say and control over what was happening to you and (2) maybe reduced or stopped the need for being sectioned?

(1) I don’t think so overall. Possibly a better attempt made to explain to me what drugs were being administered to me and why. I was never told. (2) Better outpatient psychiatric care, notably being better listened to and believed by the psychiatrist; seeing a psychiatrist more frequently so that s/he see me present as hypomanic as well as depressed; having a more compassionate CPN team concerned more about my well-being than about getting someone off the books asap due to limited resources.
Was there any way of stopping the need for compulsory treatment at that point where you had gone high?

No, not once I was that high. With hindsight I believe I would have been put less at risk had I been sectioned sooner (see further on).

However, several things could have obviated the need for sectioning:

Having a better therapeutic relationship with my psychiatrists, from 2010 on. On several occasions I was variously patronised, not listened to properly, judged and treated dismissively. Too much deference to my first psychiatrist perhaps? – an esteemed head of perinatal psychiatry. Had my bipolar condition been diagnosed sooner, I would have had access to Lithium and this would have reduced the chance of my going manic. Further I would not have been given an antidepressant – Venlafaxine – unsuitable for bipolar depression which triggered the mania that culminated in my sectioning.

Seeing a psychiatrist more regularly: every 3 months I presented, with depression. No psychiatrist actually saw me high, until I was hospitalised.

Better CPN team. While I was fortunate with the nursing staff in hospital, my Community Team was poor. One of the three CPNs I had was good and that was subsequent to my section. It was made clear to me that I was taking up resources and that there were others more in need the team ought to be servicing. On my last meeting with the CPN in XXXX, prior to hospitalisation, I again said that I believed I was bipolar and he retorted: ‘Stop saying that. Nobody thinks you are bipolar. Only you.’ He then discharged me, and in less than 2 months I was sectioned.

Faster hospitalisation – I should have been hospitalised on 19th November, when first given an emergency appointment with a psychiatrist rather than 26th November. On the 19th my psychiatrist recommended I stay away from my mother, have some peace, perhaps go to a hotel for a week, and go swimming. I was ‘artistic’, not ‘bipolar’. I needed peace, not hospital. On the 26th November my brothers managed to get me accepted by hospital via A&E. (In the interim, various members of my family had been staying in the house with me 24/7.)

Being informed more regularly by family and the children’s father of what was happening with the children: who they were with, how they were, what they were doing. Once in the ward I wanted to escape and I did escape once, and then signed myself out (since I was then a voluntary patient) on 31 November (detailed further on). I think the main reason I wanted out of the hospital was due to the violence of the separation from my children. Nothing was explained to me; we were just suddenly cut off from each other. Fortunately, nursing staff did intervene at a later point to insist that the children’s father facilitate phone calls every evening so that I could hear them play.

This was more a family than a health service issue. However, perhaps staff could have guided my family at little in how to deal with communication about and with children.
It was not enough that I and the children separately were in our respective places of safety in terms of shelter, food and (for me) medical care. Some care needed to be given to use regarding managing the separation – perhaps talking therapy, or, for the young children, some form of play therapy.

• Impaired decision making –

What does this mean to you?

Decisions made based on flawed thinking and feeling. The person making the decision is not able to ‘think straight’ due to mental ill-health. Decisions can be uncharacteristic, rash, irresponsible, risky etc without it ever occurring to the decision-maker at the time that this is the case.

The person has no insight that her/her decision-making is impaired. In mania I was utterly convinced at times that my decisions were good, and could not have been persuaded otherwise.

How did you experience it?

When I was in mania part of me believed and trusted that I was acting rationally. At points I was aware that my behaviour was out of the ordinary, but at those times I just thought I was more insightful or enlightened than I had been at other points in my life. My capacity to listen diminished. My speech was pressurised, and I talked without stopping to those who would listen. I was not aware that I was doing this.

With the inflated sense of self that comes with mania, I also considered myself to be very interesting. This explained why so many of the nursing staff were coming to talk to me; except that in reality I was under ‘close observation’ and the staff were on a rota to monitor me.

One’s reality is impaired. It is out of kilter with that of most adults. Consequently, one’s decision making is impaired.

Examples of my impaired decision making during acute mental illness:

In the lead-up to hospitalisation I could be totally disinhibited in word and text. I jeopardised my career; certainly, my actions affected my reputation. But at that time, it just seemed important to express particular things, and I wished for a sympathetic audience. In the context of my work (I was a university lecturer), I emailed confidently colleagues much more senior, about matters that did not concern me but about which I thought I had good ideas.

Once in hospital, my access to a smartphone, a computer and the internet was removed, and this protected me from causing more self-harm in effect.

For example: There was a radio phone-in. I called in, introduced myself, my home town and my profession and then began raving, not just about the programs subject, but about domestic violence, hatred in the west of Scotland… The presenter ended
my contribution, but several people I know had heard me on the radio and got in touch with my family.

Around this time, I sent a long email about various parts of my family’s history and some links to literature and to all in my address book I sensed might be receptive, including a number of lecturers and professors in my field. At the time, the process seemed necessary and cathartic. In reality, it was unhelpful and misjudged. I am still living with the embarrassment of some of these actions. The removal of my access to internet and phone services (except use of the phone in the nurse’s bay and use of a pay as you go basic Nokia with only a few safe numbers in the memory) was important for my well-being long-term.

When my brother leant me his phone, just after the section had been ended, I posted on my Facebook account a picture of us both, with the caption ‘Section’s Up’. All my contacts could potentially have seen that I was in a psychiatric ward and had been under section.

Impaired decision making does not mean that there is no rationale at all. It’s just that the person may be deciding things based on rationales that are not obvious to most observers. So, on 13 November I left some friends after the going out with them, went to Marks and Spencer’s, and proceeded to spend over £800 before closing. A month prior I was still in the throes of a suicidal depression. During this period I was incapable of buying clothes for my children. I could not see beyond material and hangars, had no conception of size or what they needed. Everything was drained of colour. My brain was frozen up. Suddenly, by the November, and catalysed by the antidepressant Venlafaxine, depression gave way to mania. I acted swiftly, thought quickly and was decisive. In M&S that afternoon, I bought Christmas gifts, children’s clothes (for 2 years down the line too), and 6 pairs of boots for myself: suddenly taste and pleasure in objects had returned. This shopping spree was a celebration of being out of the dark, of being out of the tortured stasis that very nearly took me away, and it was a celebration of life, giving and flow – concepts unavailable in the stark stagnation and disconnection of depression.

Spending vast amounts of money is a feature of mania. People can find themselves in terrible debt on the back of a manic episode. This impacts on families. Decision-making has been impaired in one sense, yes; but it has followed the existential logic of the illness.

In hospital, I had no money for a spell. Then the nurses kept my limited spending money I had and I could sign it out. I did not have my bank card. I do not know whether this was my mother’s decision or that of the medical staff.

Another time when I was protected from my impaired decision making was when, divested of internet and phone, I was sending out letters or packages to friends whose addresses I could remember, and the staff screened what was going out.

**How could people have responded better to this?**

On the whole people responded well to my impaired decision making and tried to contain me where they could.
But I also needed some way of living out some of the actions I felt impelled to do. For example, had someone stopped me from buying £800 of items from M&S at the time, I think I would have got angry, felt misunderstood and hurt, and felt less trusting and more estranged from the person stopping me.

Had I been given access from the beginning to writing materials and a pad, I would not have written on the walls. I would not have been distressed when my writing was wiped from the walls, without my being allowed to note down what I’d written. I’d just come out of a depression where one reason for my not having completed suicide had been my inability to pen a suicide note. Somewhere in me, at the time, I knew that words mattered to me and that it would not be right to exit life without a letter. So when words came back to me, at speed, as though they were flowing through me, it was vital that they be cherished, harnessed, looked after.

When a nurse was wiping away the words in marker pen scrawled on my room wall, I felt like a part of me was being wiped away. Staff weren’t listening. I couldn’t explain myself well. I tried to stop the cleaning. A nurse intervened, pinned down my arms and I head-butted him.

He did not wish to press charges, but my assault infringed the Emergency Workers (Scotland) Act 2005 and the matter was taken out of his hands. After hospital the court hearings continued for over a year until the case ran out of steam. The process was expensive, time-consuming and stressful, not least at a time when I was working on my recovery.

Ideally, my request to have access to writing materials would be a feature of my Advanced Statement. At the time, I did not have one in place. Initially, my request was thought to be absurd.

Regarding money, I would like to have been told what my rights were in relation to my access to my money. As it was, my mother seemed to regulate this. She thought it not necessary that I have any money as I was being fed in hospital. I think the psychiatrist recommended later that she make some money available to me. I remember that when my children were brought to visit I had to ask for some coins from other patients to buy the kids some chocolate. I remember also stealing newspapers and magazines from the hospital shop. I also remember offering to take a woman’s trolley back in the Lidl car park and saying that I’d give the £1 to the hospice, when in fact I spent it in Lidl on chewing gum. I imagine that because money is such an issue with bipolar, I was being managed closely. However, it did feel like clumsy management (possibly on my mother’s part), and a further loss of agency. This would be an appeal to be treated with more dignity by services, but also by family.

How should they respond?

Perceptions are skewed in mental illness, but you are wed to these perceptions because they are all you have; that is your only mode of access to understanding the world and yourself. Staff should appreciate that, perhaps try to follow the patient a
little in his/her logic, try to understand it, and only then gently suggest to them a more normalised perspective. Essentially staff should be open-minded, good listeners, and not be overly dismissive of ways of seeing that are at odds with the norm – all this, while keeping themselves and their advice grounded.

**Need to accelerate compulsory treatment:**

I believe I would have been better protected had I been sectioned earlier. On the evening of 31 November, my 7th day on the ward, still wrongly diagnosed, and so without Lithium, I was shouting and swearing in the corridor. I was told by a member of staff that I didn’t have to be there, that I was a voluntary patient and that I could sign myself out. I immediately said, ‘Where do I sign?’. The psychiatrist on duty signed part of a form and I signed another. By this time the police had arrived, probably due to breach of the peace. I put my things into two bin bags and left with the police. I was talking rapidly. I said to the police that it must be a busy night for them. They agreed. Whether at my suggestion or their own – I do not recollect – rather than drive me home, they stopped in front of the hospital reception and told me I could go in there and call a taxi. When they drove off I turned in the other direction. It was a beautiful starry night and adventure beckoned (this is a manic person thinking). I dumped my bin bags by the side of the stairway out of the hospital. I walked towards the train station. I had no money, no phone. I threw stones up at a flat window and a woman looked out. I explained my situation and she came down and gave me £3, all that was in her purse and told me to go back to the hospital reception. I then walked through snow-covered paths into woodland.

Eventually I was back by a main road, cold and hungry, and went to a McDonalds Drive Thru (the restaurant was closed). They wouldn’t serve me because I wasn’t in a car. I then realised I’d lost my coins. I was so in need of calories I ended up drinking strawberry milkshake out a bin. I walked across the dual carriageway to another fast food place where people were closing up. I wanted to borrow a phone to phone my dad. A passerby lent me his phone and I called my uncle and left a message on my mother’s answer phone. I could only remember landlines. Shortly after my brother found me by the road. He took me to McDonalds to get some food in me, and also to ask for my necklace back (I’d tried to pawn it earlier for chips).

The Police were there because I’d shouted earlier at the manager when he wouldn’t allow me to be served because I wasn’t in a car, and they came to berate me.

My brother told them that their colleagues had left me outside the hospital. My brother got me back to the hospital. I was in A&E and then, warmed up, back on the ward, but this time I was given my own room. I think the section was put in place following that. It would have been better had it been in place before.

Cf: [http://www.heraldscotland.com/news/15573676.Depressed_patient_took_own_life_at_Hogmanay_after_psychiatrist_said_he_was__faking__symptoms/](http://www.heraldscotland.com/news/15573676.Depressed_patient_took_own_life_at_Hogmanay_after_psychiatrist_said_he_was__faking__symptoms/)
Extra material related to the questions asked

Lived experience: I was diagnosed bipolar during a hospital stay of 7 weeks from 26 November. Initially I was a voluntary patient, but I was sectioned in the December for 3 weeks. My bipolar diagnosis was made towards or just after the end of the section. I was given Lithium for the first time and that reduced my mania. During the section I was visited by a lawyer, recommended by a friend, and by advocacy services.

I felt safe and in good hands largely. I felt that this was the best way of getting help. I felt like I was being allowed to abdicate responsibility – over myself, my children and my job – in order that space be given to longer-term healing. I felt like my distress, that had been ongoing in an acute way for me for 4 years, was being taken seriously finally and that services knew how to support me. I felt grateful. This could have been due in part to my mania, a symptom of which is at times expansive empathy. I did not feel frightened. At points I felt bemused that I could be in such a situation.

The hospital, the ward and – at the most intense period – the section held me when the world was too much for me and I was too much for the world. By the world I mean outside civilization and society.

In the September preceding my time in hospital I had attempted suicide through hanging. I told nobody of it at the time. This was the worst my depression has been. In a sense, suicide was an attempt to find relief by leaving my suffering, my responsibilities and the world. In a partial parallel, and in the context of my being in a manic episode, the section accorded me relief by taking from me, for a limited time, all responsibilities, and that in a space where I trusted that professionals were working to relieve me of my mental suffering. I was given a space in which all I could do, divested as I was of most rights, was to be; to focus on myself; to rest; to stop worrying about those – specifically my children – who normally depended upon me. The state, it seems to me, was recognising that I needed these loads – rights and responsibilities – lifted from me for a period in order to better function in the long term. I did not experience my sectioning as menacing particularly, but rather as benign. At that point in my life, I felt safer contained.

I knew I needed looking after, that my mind was unhinged, that my behaviour was erratic and so potentially dangerous in the outside world. For example, in mania I have walked down middle barriers of dual carriageways; I have crossed dual carriageways on foot; I have run away from the hospital in pyjamas when snow was underfoot, without phone and money.

Sectioned I felt looked after and closely observed. No-one was dismissive of my suffering. My suffering was being recognised. This contrasts with how I had experienced years of psychiatric care as an outpatient, when the wrong diagnosis – and so the wrong medication – was peddled for three long years. This was a time when I presented at my 3 monthly-appointments to various psychiatrists (little continuity in who saw me) and was in depression, expressing myself poorly, specialists knowing little of who I am, and all being dismissive of my faltering descriptions of hypomanic behaviour. The series of
psychiatrists, reading each other’s notes, insisted I did not have bipolar disorder, but rather adjustment disorder.

Held, or rather, firmly contained in hospital, 24/7, the nursing staff and psychiatrist could observe my behaviour and recognise that it was that of a manic depressive.

Gosport War Memorial Hospital: old people overdosed on opioids, apparently to reduce bed-blocking... This hospital was ‘the end of the line’. Whistle-blowers and kin were treated with contempt and their complaints dismissed, while murderous malpractice was protected and prolonged by a number of complicit agencies. Bishop James Jones who headed the inquiry used the term: ‘The Patronising Disposition of Unaccountable Power’.

Perhaps in part due to such examples (far and few between, but present nevertheless), the idea of sectioning is anathema. The power imbalance is almost total: the law empowers health agencies with regards to you, while you are almost totally disempowered. In this Gosport context, health agencies could not be trusted; nor could they be questioned.

Mitigating factors to this disempowerment I was aware of are that you are offered an advocate to speak for you; that you are given the chance to have a lawyer visit to explain to you your situation; that you may have an ‘advance statement’ form logged, aspects of which may be taken into account regarding your care.

Trust is required by the patient and by the patient’s kin that the health agencies do have the patient’s best interests in mind, and that they will endeavour to communicate as best they can in a two-way manner with the patient and the patient’s named person or next of kin. This was my case.

The psychiatric ward in the NHS hospital for me felt maternal in some ways. There was during my 7 weeks stay there (of which 3 weeks were under section) a kind of regression to a safe, secure place: I was rendered helpless (like a baby). The section sought to contain my mania and safeguard me and others from my own risky behaviour. It was like being held, while I gathered myself back together, rested and healed. Held, not in the sense of prison bars, but rather that of being held by someone who is looking after your well-being and who considers your well-being important.

The section was put in place because: I could not control my racing, mal-functioning brain; those around me – friends, family, colleagues – were out of their depth at keeping me safe at home; my young children would have been exposed to bizarre risky behaviour on their mother’s part (e.g. cooking soup on the hob, then being distracted by my next all-absorbing project, and burning the pot; or driving erratically).

Moreover, hospital staff were unable to contain me initially as I escaped the premises, in nightwear during snowy weather, with no money or phone. Holding me under section meant that staff could watch my movements more closely. It also meant that I was safer, as were the public – e.g. having little sense of risk at the time, I could have walked in front of a car and endangered more lives than my own.
When I was experiencing mania, I was expansive, and my attitude to many things and people was positive and engaging. I talked with many of the other patients and staff. I enjoyed visits from friends and family. I was also relieved finally to be taken seriously by staff, after having been treated dismissively at points by the series of outpatient psychiatrists I had seen prior, who tended to join ranks and read more their colleagues’ notes than listen to me as a patient (subsequently, my psychiatrist agreed with me that this had been the case). This attitude was taken up by two CPNs too. In general, I was looking favourably on the attention I was receiving.

It was a turning point in my diagnosis. It allowed me to be closely observed and finally, towards the end of the section, be given Lithium, which reduced the mania. I had for four years been so anxious to get proper treatment for what is wrong with me, not least because I was bringing up small children and desperately needed to be well for them, or as well as can be.