

The Mental Capacity Act: Supporting People with PWS

Introduction

Although people with PWS are capable of making decisions about many areas of their life, dysfunction in areas of the brain that control eating behaviour and energy balance means that they will rarely have the capacity independently to make decisions about eating. Even if they can make a decision at one point in time, this may not be the case at other times, particularly in the absence of supervision or environmental restrictions on access to food.

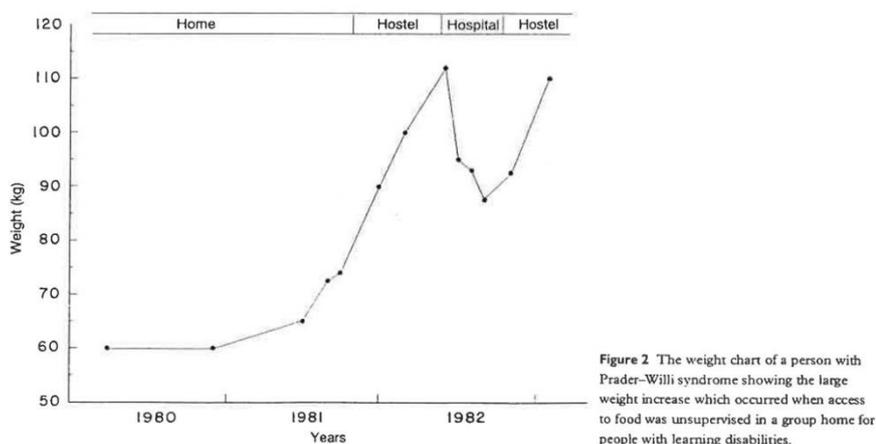
This [MCA Overview video](#) offers a brief useful introduction to the main elements of the Mental Capacity Act.

Although the Mental Capacity Act (MCA) has implications for other aspects of PWS, this article will focus on the possible relevance of the MCA in the management of the over-eating behaviour and risk of life-threatening obesity associated with the syndrome.

Key questions to consider are:

- Does the fact that PWS is a genetic disorder make PWS different from other kinds of obesity?
- Should people with PWS be treated differently from others with respect to their risk of obesity?
- Is it acceptable to control access to food and is there a responsibility on families and other carers to manage the food environment?

Making decisions about food and PWS



The diagram shows the first piece of research undertaken by Professor Tony Holland in the 1980s, which graphically shows the increase in weight experienced by a young woman with PWS after she left home and went to live in a hostel, followed by a spell in hospital, and then back to the hostel again.

Her diet had been controlled in her home environment but was not when she left home. This type of scenario has subsequently been repeated many times over with different people with PWS, and clearly illustrates the risk if people with PWS are not on a diet and are not living in a food managed environment.

The consequences of having uncontrolled access to food has been backed up by this and subsequent research, such as that conducted by Ella Hinton (1) and others, which showed, using brain imaging, that the response in the brains of people with PWS to having eaten food is abnormal - it is as if the brain doesn't recognise that the person has eaten. These research observations raise challenging ethical and legal questions, which we will explore in detail.

Existing legal and ethical considerations for people with PWS

Human Rights Act

Government legislation, judicial decisions and professional judgements made by/on behalf of public bodies have to be compatible with the Human Rights Act, some of whose articles are as follows:

- Article 2: Right to life
- Article 3: Freedom from cruel and inhumane treatment
- Article 5: Right to liberty and security of person
- Article 8: Respect for private and family life, his home and his correspondence
- Article 9: Freedom of thought

In arriving at a decision in contested cases, professionals and the courts may have to balance one right against another. An example is the right to life. If treatment will at best only prolong life for a few days but will result in considerable discomfort, does the right not to be subjected to cruel and inhuman treatment outweigh a right to life?

It is also important to remember that questions regarding a person's mental capacity may also begin to interfere with a person's autonomy, which is, in part, protected by Article 8 of the Human Rights Act, specifically your right to 'respect for private life'. For this reason assessments of capacity and best interest decisions must always be followed in order that any invasion into this person's autonomy can be justified through a procedure prescribed by law, and any invasion must always be necessary and proportionate to the risks against which the person is being secured, and open to challenge. In England and Wales an example of how these decisions can be justified in law is through the use of the Mental Capacity Act.

The Care Act

Social care professionals must consider the 'wellbeing' principle outlined in the Care Act (2014).

As the Care Act identifies, the core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life. Underpinning all of these individual 'care and support functions' (that is, any process, activity or broader responsibility that the local authority performs) is the need to ensure that doing so focuses on the needs and goals of the person concerned.

The Care Act describes 'wellbeing' as relating to the following areas in particular:

- Personal dignity (including treatment of the individual with respect)
- Physical and mental health and emotional wellbeing
- Protection from abuse and neglect
- Control by the individual over day-to-day life (including over care and support provided and the way it is provided)
- Participation in work, education, training or recreation
- Social and economic wellbeing
- Domestic, family and personal

- Suitability of living accommodation
- The individual's contribution to society

NB: For practitioners working in Wales, please refer to [Social Services and Well-being \(Wales\) Act 2014](#).

Valuing People

In addition, there are various other government policies and legislation that needs to be considered. Key ones with regard to people with learning disabilities in England are "Valuing People and Valuing People Now", which set out the following principles:

- Rights (e.g., human rights; freedom from discrimination)
- Independence (e.g., starting presumption is one of independence not dependence)
- Choice (e.g., direct payments, choice of services received)
- Inclusion (e.g., use of mainstream services)

Consent

Consent is a fundamental principle of medical and social care law. An adult has the right to determine for him/herself what should happen to his/her body – the principle of autonomy (self-determination) ([Mr C \(1994\)](#) and [Ms MB \(1997\)](#)).

Failure to consider the principles of consent in health and social care decision-making could lead to a claim of negligence against the professional, a complaint, a safeguarding inquiry or even civil or criminal proceedings.

There are three components to valid consent:

- The giving of information
- Voluntariness
- Capacity

Case law

Various instances of case law have taken this into account. In these cases, the underlying principle is that consent from an adult is crucial to making a decision "lawful".

In the case of Mr C, he was in Broadmoor Special Hospital diagnosed with schizophrenia. He had diabetes and his leg had become gangrenous. The surgeon recommended that he have it amputated, as there was an 85% chance of death if he did not. Mr C contested this, saying he did not want his leg amputated. The Court upheld Mr C's appeal, as it was deemed he had capacity to make decisions about his physical health. In fact, Mr C subsequently left Broadmoor with both legs intact.

In the case of Ms MB, she had a phobia of needles and was refusing to have a Caesarean section, even though her life and that of her unborn child were at risk. In her case, the Court ruled that she lacked capacity to make a reasoned decision as her phobia overwhelmed everything else and it would not be unlawful for the hospital to proceed without her consent. She had the Caesarean and both she and the child survived.

The Mental Capacity Act 2005 - Overview

Given this principle of self-determination and the fact that it is consent that enables treatment to lawfully take place, the problem that then has to be considered arises from the fact that developmental (i.e., learning disabilities), acquired neurological (e.g., strokes; unconsciousness)

or psychiatric disorders (e.g., profound depression, dementia) may result in an impaired ability to make a decision or the person may be unable to communicate his/her choice.

Hence the following questions arise:

- Under what circumstances should there be decisions made in a person's best interests and what principles should be applied when making a decision on behalf of another, when it would normally have been for that person to make the decision?
- In such circumstances, how then to achieve a balance between respecting individual rights (self-determination) vs protection against harm or neglect, abuse, and/or exploitation?

The MCA, as a solution to this problem, was first proposed in the mid-1990s as a means of providing a statutory framework to enable decisions to be made on behalf of people who lack decision-making capacity and also to establish guidance as to the determination of capacity and of what was meant by "acting in someone's best interests". Such a law would also provide the means of challenge when opinions about capacity and/or best interests were disputed. It took 10 years of debate, discussion and consultation to finally become an Act of Parliament - the Mental Capacity Act 2005.

Much of the Act put into statute existing common law and therefore the principles enshrined in the Act should have already been guiding health and social care practice.

The MCA is concerned with people aged 16 and over who may lack decision-making capacity, and those aged 18 who (having capacity) may wish to make advanced decisions or appoint lasting power of attorneys (LPAs) in the event of future incapacity.

Lasting Powers of Attorney can be done by appointing someone, or more than one person, to act on your behalf for decisions involving health and/or property and financial affairs in the event that you develop an illness or suffer an injury that affects your ability to make decisions.

The MCA is very important for those working in health or social care settings, as all those working in a professional or caring role with a person found to lack the capacity to make a particular decision, or who is undertaking an act that is required to be undertaken or done, must have regard to the MCA and its Code of Practice.

Where someone lacks the capacity to make a particular decision the MCA allows for acts in connection with care and treatment to take place providing they are in the person's best interest. The MCA does not strictly provide the authority to act, but rather a justification for acting and therefore protection from liability. It is meant to be empowering rather than restricting.

Under the MCA, the Court of Protection also has the power to make decisions where there are disputes and to appoint **deputies** to make a particular decision with respect to specific situations. When determining what is in a person's 'best interest' the person requiring the decision to be made must consider a number of factors, including the past and present ascertainable wishes of the person concerned, as well as the views of relevant others. An action must be the least restrictive that is appropriate.

The five basic principles of the MCA

Section 1 of the Mental Capacity Act sets out five 'statutory principles' – the values that underpin the legal requirements in the Act.

1. A person must be assumed to have capacity unless it is established that he lacks capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Consent / autonomy and diet

However, the dilemma of what to do to prevent obesity remains and can be extended to other forms of obesity in addition to that associated with PWS - as well as to the converse, not eating, i.e: anorexia nervosa.

Can an adult lawfully be forced to diet in the absence of consent, when not to diet is associated with a significant health risk? For example in cases of:

- Simple obesity - there are no laws pertaining to this
- Diabetes mellitus - similarly there are no laws pertaining to this
- PWS

Ethics and PWS

As evidenced above, there are no laws that apply specifically to children and adults with PWS. We are therefore left with several topics for debate, which include:

- In childhood what responsibility do the parents have when caring for a child with PWS? If an early diagnosis is made, how far is it the parents' responsibility to prevent the child from becoming obese?
- Is having PWS different from having obesity for other reasons? If it is not, then it is hard to argue that forced dieting is appropriate or necessary.
- Do adults with PWS have the capacity to make decisions about eating and to keep to such decisions?
- Are people with PWS vulnerable? Should the state intervene and if so on what basis?
- Is the right to life so important that the liberty of a person with PWS should be limited in order to prevent severe obesity and its life-limiting consequences?

Examining the issues with regard to people with PWS

When considering these issues it may help if professionals consider the following questions:

- What is your duty to this person?
- What decision does he/she need to take and does he/she have the capacity to take that decision?
- If he/she has capacity how can you encourage him/her to manage food intake and prevent obesity?
- If he/she lacks capacity to make decisions about food what is in his/her best interest and what is the least restrictive option?
- What legal framework should be used?

Responsibilities of carers and the Local Authority

What responsibility do paid care professionals and the Local Authority have with respect to managing the eating behaviour of an adult with PWS? It is not enough to simply state "It is their choice".

At the very least those providing services need to consider their responsibilities particularly with regards to the MCA if it is possible the person concerned lacks capacity (this would apply for people aged 16+).

A minimum response might be at least to find out about the syndrome and to consider whether the person has the capacity to make the necessary decision or not. If they don't have the capacity to make such decisions then there is a responsibility to act in their best interests.

Managing the eating disorder in PWS over the lifespan

Children

In childhood, parents or strictly those with parental responsibility have a duty to act in the best interests of their children. This is encapsulated in The Children Act (1989). Hence with the early diagnosis of PWS and with full knowledge of the risks of the syndrome, families could be seen to have a duty to manage the eating environment. It should also be acknowledged that where a child is 'Gillick competent' that they may be able to consent to some aspects of their care and or treatment.

NB: When considering children consenting to medical treatment or care, the terms 'Gillick competence' and 'Fraser guidelines' are frequently used interchangeably despite there being a clear distinction between them. Gillick competence is concerned with determining a child's capacity to consent. Fraser guidelines, on the other hand, are used specifically to decide if a child can consent to contraceptive or sexual health advice and treatment. To find out more about 'Gillick competence' click [here](#).

Young Adults (16 and 17 years old)

The MCA Code of Practice states:

The Act's starting point is to confirm in legislation that it should be assumed that an adult (aged 16 or over) has full legal capacity to make decisions for themselves (the right to autonomy)

unless it can be shown that they lack capacity to make a decision for themselves at the time the decision needs to be made.

As such, when a young person reaches the age of 16, they should be assumed to be able make their own decisions in every aspect of their life. So when a young person reaches the age of 16 in cases of PWS, family carers and care professionals may have to start to consider the young person's mental capacity to make decisions about the management of their over-eating behaviour, their diet and potential risk of obesity.

However, as the MCA Code of Practice identifies there may be some circumstances that are difficult to determine with this age group. For example it might be appropriate to refer a case to the Court of Protection where there is disagreement between a person interested in the care and welfare of a young person and the young person's medical team about the young person's best interests or capacity. This could on occasion be a consideration for those supporting people with PWS.

If a young person has capacity to agree to their treatment or care, their decision to consent must be respected. Difficult issues can arise if a young person has legal and mental capacity and refuses consent – especially if a person with parental responsibility wishes to give consent on the young person's behalf (for example, a person with parental responsibility wanting to consent to a regime that forces the young person to diet where the young person refuses that support).

The Family Division of the High Court can hear cases where there is this type of disagreement. The Court of Protection has no power to settle a dispute about a young person who is said to have the mental capacity to make the specific decision.

NB: The law in this area is constantly changing and it is vitally important that professionals keep themselves updated. Free and invaluable summaries of Court decisions that may impact on your professional practice can be obtained from:

- [39 Essex Chambers](#)
- [SCIE](#) (Social Care Institute for Excellence)
- [RiPFA](#) (Research in Practice for Adults)

Adults (18+)

From the age of 16 and into adult life (18 or over), there is a dilemma with regards to the support of people with PWS between respect for autonomy (self-determination) and the need for care and/or treatment.

In the general population it would be considered wrong to force a person to diet - is this also true for those with PWS?

How might this tension between respect for autonomy and the major risks of life-threatening obesity, if the now adult person with PWS is allowed free access to food, be resolved? There are several possible routes with the potential for increasing involvement of the legal system, which is discussed later.

Legal consideration in managing the eating disorder in PWS

Action by consent

This is probably the best way for supporting people with PWS in managing their eating disorder. This can be seen in practice in the case of people with PWS who are living in PWS specific homes - ie, those with PWS who have eventually consented to live in these homes (sometimes after great resistance) and appear then to appreciate the benefits that that type of environment offers.

This has been well illustrated in TV documentaries on PWS and also in recent research by Becca Hawkins (2), a social anthropologist in the Cambridge research group on PWS. She has explored how people with PWS and support staff negotiate living together in such settings.

Issues of Mental Capacity in cases of PWS

Section 2(1) of the MCA states:

"A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or disturbance in the functioning of, the mind or brain."

Within the framework of the MCA, decision-making capacity is determined for each decision at a particular point in time. This acknowledges that people are capable of making decisions about some things but not about others, and that they may be able to make decisions at some points in their lives, but not at others.

Our knowledge of PWS is such that we can say this is true for people who have the syndrome: they may be able to make many decisions but, for example, may not be able to make a decision about the amount of food to eat. In the context of the MCA this determination of capacity is to be carried out by the person requiring the decision to be made - for example, a doctor in the case of health treatment.

Inability to make decisions

Section 3(1) of the Mental Capacity Act states that:

... A person is unable to make a decision for himself if:

- a) He is unable to understand the information relevant to the decision;*
- b) He is unable to retain the information relevant to the decision;*
- c) He is unable to use or weigh the information relevant to the decision as part of the process of making the decision; or*
- d) He is unable to communicate the decision (by talking, sign language, or other means).*

When assessing a person's decision making capacity the following applies:

- There must be evidence of a disability that might affect capacity. The MCA Code of Practice asks us to consider whether the person has an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? It doesn't matter whether the impairment or disturbance is temporary or permanent. As argued earlier, it would be reasonable to argue that a diagnosis of PWS is evidence in itself even where there is no dual diagnosis of an intellectual disability. The presence of such an impairment is not sufficient in itself to decide that someone lacks the capacity to make a specific decision, but it is a necessary requirement.

- As identified above, a functional approach must then be taken that assesses the person's ability to make this decision at this time (rather than determined by status, such as diagnosis, or outcome, such as whether you agree with what he/she has decided (Principle 3 of the MCA)).
- Finally, it is vital to consider whether you are satisfied that the inability to make a decision is because of the impairment of the mind or brain (this is often referred to as the 'causative nexus')? So there has to be (and you have to show that you are satisfied why, and how there is) a causal link between the disturbance or impairment and the inability to make the decision(s) in question.

Decision-making capacity and PWS

In any given situation, to judge whether someone has the capacity to make the decision in question, it is important he/she is appropriately informed. The following outlines the type of information that should be given.

- Nature of the decision
- Purpose of the decision
- Risks associated with the potential outcomes of a decision one way or the other
- Other options

In assessing that person's capacity, you then ask them to explain these particular issues that they have been told about and ask them to consider/explain how these factors apply to their current situation.

If the MCA was to be used to determine that a person with PWS had to live in a food restrictive environment (in their best interests), it would have to be demonstrated that the person concerned lacked the capacity to make a decision about managing their diet and food intake (within the context of life-threatening obesity).

Whilst people with PWS may understand the issues of their condition, it could be argued in certain situations that some people with PWS (even where there is no dual diagnosis of an intellectual disability) are unable to use and weigh up the information to arrive at a decision. There has now been one case of a person with PWS being heard by the Court of Protection and also in Scotland under the Adults with Incapacity (Scotland) Act. In both cases the courts agreed with such a proposition.

The argument that could be put forward in cases of PWS is that, whilst a person with PWS may recognise that obesity carries risks, it is often unclear whether or not he/she is able to appreciate the potential for excessive eating and resultant obesity if access to food was not controlled or have an understanding of the serious complications that would arise if they were to become obese. In addition, it is highly likely that, under circumstances where food security was not in place, the anxiety associated with free access to food and the associated increased preoccupation with food would mean that the person would certainly be unable to weigh or use the relevant information and arrive at a choice at that moment.

So, if we were to use a clinical model to explain the above, it could be argued that a person with PWS may be able to understand and retain information in relation to their diagnosis but they would still be unable to either apply the potential diagnosis and prognosis to themselves and their current situation, or use the information regarding the risks associated with their diagnosis at the time it is required because of the effects of having PWS.

You can split issues of capacity in PWS to two specific groups:

- 1) those who have an intellectual disability which may contribute to them being unable to understand information about their diagnosis and/or communicate a decision in relation to the matter, and;
- 2) those with or without intellectual disabilities who are able to understand their diagnosis and even prognosis but struggle to use and weigh information in relation to the support they need to manage their condition. It is in these cases where we must ask ourselves is the person unable to use or weigh the relevant information? This has often been described as the most difficult component of the assessment of capacity to determine.

The following summarised guidance from 39 Essex Chambers '[A Brief Guide to Carrying out Capacity Assessments](#)' may support practitioners when considering this issue with PWS. They explain that:

This aspect of the test has been described as 'the capacity actually to engage in the decision-making process itself and to be able to see the various parts of the argument and to relate the one to another.' As with understanding, it is not necessary for a person to use and weigh every detail of the respective options available to them in order to demonstrate capacity, merely the salient factors. Therefore, even though a person may be unable to use and weigh some information relevant to the decision in question, they may nonetheless be able to use and weigh other elements sufficiently to be able to make a capacitous decision.

It is particularly important here to be aware of the dangers of equating an irrational decision with the inability to make one – P may not agree with the advice of professionals, but that does not mean that P lacks capacity to make a decision.

Further, if a person is able to use and weigh the relevant information, the weight to be attached to that information in the decision making process is a matter for that person. This means you need to be very careful when assessing a person's capacity to make sure – as far as possible – that you are not conflating the way in which they apply their own values and outlook (which may be very different to yours) with a functional inability to use and weigh information. This means that, as much as possible, you need as part of your assessment – your conversation – with P, to glean an idea of their values and their life story as it relates to the decision in question.

In some cases, it may be difficult to identify whether P is using a piece of relevant information but according it no weight, or failing to use the piece of information at all. Psychiatric expertise may be of assistance in such cases, as it may explain whether P's ability to process information is impaired and if so, to what extent.

Another common area of difficulty is where a person with an acquired brain injury gives superficially coherent answers to questions, but it is clear from their actions that they are unable to carry into effect the intentions expressed in those answers (in other words, their so-called executive function is impaired). It can be very difficult in such cases to identify whether the person in fact lacks capacity within the meaning of the MCA 2005, but a key question can be whether they are aware of their own deficits – in other words, whether they are able to use and weigh (or understand) the fact that there is a mismatch between their ability to respond to questions in the abstract and to act when faced by concrete situations. Failing to carry out a sufficiently detailed capacity assessment in such situations can expose the person to substantial risks.

Mental Capacity / Executive Functioning and PWS

One of the ideas mentioned above is executive functioning. In simple terms, this is when a person comes to carrying into effect what they have said they would carry out. The ability to do this requires the use of cognitive abilities that are termed 'executive functions'. When assessing someone's capacity and how he/she is able to describe what the decision involves and balance the pros and cons of a given course of action, you will, among other skills, be assessing their executive functioning. Executive functioning is not directly part of the functional test of capacity; however, having these abilities is necessary in order to make what may be quite complex decisions. It is therefore a very useful area to explore when working with people with PWS, who have been shown to have impairments in this area, and judgements about the person's abilities in these areas may help you provide clear evidence when completing a capacity assessment.

Executive abilities or functions allow people to mentally play with ideas, for example:

- taking the time to think before acting;
- reacting to unanticipated challenges;
- resisting temptations;
- staying focused.

Core executive functions are:

- inhibition - response inhibition (self-control—resisting temptations and resisting acting impulsively) and interference control (selective attention and cognitive inhibition);
- working memory, and cognitive flexibility (including creatively thinking “outside the box”);
- seeing anything from different perspectives and, quickly and flexibly adapting to changed circumstances.

It will often be that families and care professionals have very useful anecdotal evidence that begins to explore the difficulties that people with PWS face when applying these executive functions to decisions about food. You do not have to be certain that such deficits exist - rather your judgement about capacity is made on the balance of probabilities.

Who should assess capacity in cases of PWS?

The MCA Code of Practice states:

The person who assesses an individual's capacity to make a decision will usually be the person who is directly concerned with the individual at the time the decision needs to be made. This means that different people will be involved in assessing someone's capacity to make different decisions at different times. (MCA Code of practice, Paragraph 4.38)

And continues:

But ultimately, it is up to the professional responsible for the person's treatment to make sure that capacity has been assessed. (MCA Code of Practice, Paragraph 4.40)

As the question of capacity for people with PWS relates to their ability to make decisions about the management of their over-eating behaviour and risk of life-threatening obesity, we would strongly suggest that the responsibility for assessing the person's capacity in this area will nearly always be the person's responsible health professional. In community-based settings this is likely to be either a GP, community nurse or dietitian. However, this is not necessarily straight forward as it will be the support staff working for the social care provider who are responsible

for limiting access to food. It is advisable that health and social care staff work together on such issues, particularly when they are complex and contentious.

Limiting access to food in cases of PWS

As providing support to people with PWS who lack the capacity to make decisions about the management of their over-eating behaviour will consist of imposing potential restraints and restrictions designed to limit their access to unsupervised eating it is also important to consider Section 6 of the Mental Capacity Act.

Section 6 of the Mental Capacity Act explains that where decisions are made that may restrain, restrict or deprive a person of their Liberty there will not be protection from liability unless professionals can show that these interventions are justified. The MCA Code of Practice gives guidance from paragraphs 6.40 onwards to help professionals justify their decision making.

Section 6(4) of the Mental Capacity Act states that someone is using restraint if they:

- *use force – or threaten to use force – to make someone do something that they are resisting, or*
- *restrict a person’s freedom of movement, whether they are resisting or not.*

In addition:

Any action intended to restrain a person who lacks capacity will not attract protection from liability unless the following two conditions are met:

- *the person taking action must reasonably believe that restraint is necessary to prevent harm to the person who lacks capacity, and*
- *the amount or type of restraint used and the amount of time it lasts must be a proportionate response to the likelihood and seriousness of harm.*

Paragraphs 6.44–6.48 of the MCA Code of Practice gives further explanation of the terms ‘necessary’, ‘harm’ and a ‘proportionate response’.

In cases of PWS the components of ‘necessary’ and ‘harm’ could be evidenced by explaining:

- The person’s current diagnosis and prognosis in relation to their obesity including their supporting comorbidities and,
- The evidence of their current eating behaviour, this can be gathered from the carers who support them on a day-to-day basis.

When looking at the factor of whether the restraint/restriction is ‘proportionate’ we will explore this in greater detail when we consider best interest decisions.

Capacity to make decision about care and residency in PWS

It could be argued that the Local Authority and/or the local Clinical Commissioning Group (CCG’s) have a responsibility to act in the best interests of a person with PWS when they are responsible for commissioning care services, if it can be shown that the person concerned lacks the capacity to make decisions about the support they need with their over-eating behaviour and risk of life-threatening obesity.

It is vitally important that local authorities take into account the evidence regarding the person's capacity to make decision about their diet and management of their obesity, as this will also be fundamental when considering the person's capacity to make decisions about their care and residency.

Care

Both local authorities and CCG's will have to take into account the following factors (where appropriate) when considering the person's capacity to make decisions about their care:

- a) With what areas the person under assessment needs support;
- b) What sort of support they need;
- c) Who will provide such support;
- d) What would happen without support, or if support was refused.
- e) That carers may not always treat the person being cared for properly, and the possibility and mechanics of making a complaint if they are not happy.

As we have already explained, a person with PWS will often lack the capacity to make decisions about the management of their overeating so it begs the questions for commissioners whether the person would then be able to consent to the package of care offered to them, especially as to be able to consent to the care you would have to be able to evaluate 'what would happen without support, or if support was refused'.

Where practitioners are unsure in these finely balanced situations, legal advice should be sought and where appropriate a referral made to the Court of Protection.

Residence

Whilst people with PWS may lack the capacity to make decisions about their care arrangements it is still possible for them to be able to consent to where the care is delivered, as long as the person does understand the sort of care they would receive in the service and the types of restrictions that will be put in place to manage their diet.

Best interests

If it is decided that someone lacks the capacity to make a particular decision as a result of an impairment or disturbance in the mind or brain, then those who require the decision to be made can act on behalf of that person providing that they act in his/her best interests.

The person making the determination must consider all the relevant circumstances and, in particular take the following steps:

- Consider whether the person may have capacity in the future? If so, when that is likely to be; (is the decision urgent?)
- As far as reasonably practicable, he/she must permit and encourage the person to participate, as fully as possible, in any act done for him and decision affecting him;
- If involving life-sustaining treatment, an action must not be motivated by a desire to bring about his/her death.

He/she must also consider:

- The person's past and present wishes and feelings (in particular any written statement made when having capacity);
- The beliefs and values that would be likely to influence his decision if he had capacity;
- Other factors that he would be likely to consider if able to do so.
- He/she must also take into account, if practicable and appropriate to consult:

- Anyone named as someone to be consulted;
- Carer for the person or interested in his/her welfare - previously there was no requirement to consult parents. Under the MCA, a person determining best interest must consult with meaningful others such as parents;
- Donee of an LPA;
- Deputy appointed by the Court.

We would strongly suggest that practitioners consider reading the 39 Essex Chambers [Mental Capacity Law Guidance Note: A brief guide to carrying out best interests assessments](#).

Deprivation of Liberty and PWS

In March 2014, the Supreme Court handed down judgment in two cases: [P v Cheshire West and Chester Council](#) and [P & Q v Surrey County Council](#). That judgment, commonly known as *Cheshire West*, has led to a considerable increase in the numbers of people in England and Wales who are considered to be cared for under circumstances that would amount to a deprived of their liberty. This ruling is also seen as widening the approach to deprivation of liberty in those settings and a cautious approach is recommended which, when in doubt, errs towards considering that restrictions on a person's liberty are considered as deprivation, so that the extra safeguards are in place.

If the care arrangements do amount to a deprivation of liberty and these arrangements are being made by the state (whether LA or NHS) then the actual location is irrelevant and an authorisation for the Deprivation of Liberty is required.

In order to determine whether a person is deprived of their liberty the following questions will have to be considered:

1. **Does the person lack the capacity to consent to their care, living/residency arrangements and the actual arrangements, which amount to their confinement?**

As explained above, many people with PWS will lack the capacity to consent to their care and living arrangements.

2. **Is there a deprivation? This part has 2 questions which are whether the person is:**
 - Not free to leave;
 - And,
 - Under continuous/complete supervision and control.

It is important that care providers and commissioners of care do not confuse a restrictive intervention with a deprivation of liberty. The restrictive intervention for example, locked cupboards or doors, is not on its own a deprivation of liberty but an indicator or a 'liberty restricting measure' that may or may not indicate that either the person is 'not free to leave' and/or 'under continuous/complete supervision and control'.

In cases of PWS it may at first appear that they have a lot of control in their lives. As one family who cared for their adult child with PWS put it: 'they can go out when they want, I can't see how we or the care staff are restricting them'. But, on further enquiry the family would only let him out with a certain amount of money so as to control his access to food whilst in the community (they were the person's appointee). His phone also had a tracking device on it and if he did not return home by a certain time the family and staff would make attempts to bring him back with the final step being reporting the matter to the police and they would return him. This was all done as he lacked the capacity to understand the risks of not having his weight managed and were being done in a less restrictive/proportionate way but did still indicate that

the person was not 'free to leave' and was under their 'continuous/complete supervision and control'. An example of this was given in the Supreme Court decision from a European Court of Human Rights case called *Stanev v Bulgaria*.

Mr Stanev was able to leave the building where he resided and to go to the nearest village (and indeed had been encouraged to work in the restaurant in the village where his care home was located "to the best of his abilities") and he also had been on "leaves of absence."

However, he needed to have permission to leave the care home, and his visits outside were subject to controls and restrictions; his leaves of absence were entirely at the discretion of the home's management, who kept his identity papers and administered his finances. When he did not return from a leave of absence, the home asked the police to search for and return him and he was returned to the home against his wishes. He was, in consequence "under constant supervision and was not free to leave the home whenever he wished," and was therefore deprived of his liberty.

As Law Society Guidance '[Deprivation of liberty: a practical guide](#)' suggests:

A pragmatic way of answering the question is to ask whether the person(s) or body responsible for the individual have a plan in place which means that they need always broadly to know:

- *where the individual is; and*
- *what they are doing at any one time.*

If the answer to both questions is 'yes,' then we suggest that this is a strong pointer that the individual is under continuous / complete supervision and control. This is particularly so if the plan sets out what the person(s) or body responsible for the individual will do in the event that they are not satisfied that they know where the individual is and what they are up to.

3. Imputable to the state: Are the arrangements made by a 'public body'?

It is not necessary to go into great detail about this point here, but in essence in any situation where a person appears to be deprived of their liberty and there is any state involvement at all (including where professionals are aware of arrangements being made in the family home and overseen by family members) professionals should ensure that steps have been taken to have the deprivation of liberty assessed and where appropriate authorised. Legal advice should be sought in relation to any situation where the individual is under 18.

Deprivation of Liberty Safeguards (care homes and hospitals)

The Deprivation of Liberty Safeguards apply in England and Wales only, and are used in hospitals and residential care settings in relation to those aged 18 and above. There are six assessments that have to take place before a standard authorisation can be given and one of the most important safeguards is that the person has someone appointed with legal powers to represent them. This person is named 'the relevant person's representative (RPR)' and will usually be a family member or friend. Other safeguards include rights to challenge such DoLs authorisations in the Court of Protection without cost, and access to independent mental capacity advocates (IMCAs). For further explanation and a scenario where DoLS might be used for PWS, see [SCIE Deprivation of Liberty Safeguards \(DoLS\) at a glance](#).

Deprivation of Liberty in Community Settings

The standard DoLS process can only be used if a person is in a care home or hospital setting. Since the Cheshire West ruling, if the person is living in another setting, such as supported living or their own home, it is still possible to deprive someone of their liberty in their best interests, but this will need to be done via an application to the Court of Protection. This also needs to be done if the person is either 16 or 17 years old and deprived of their liberty (this is explored further in the next section of the guidance).

The practical and procedural implications of this was considered in the first judgment of 'Re X and Others.' Where the judge sought to devise a:

"... streamlined process, compatible with all the requirements of Article 5, which will enable the Court of Protection to deal with all DoLS cases in a timely but just and fair way."

This became known as "the Re X process" as well as "court authorisations", and is how Local Authorities and CCG's get deprivation of liberty authorised in community settings.

Deprivation of Liberty and under 18 year olds

The law in this area can be slightly more complex, during this period of transition from children's to adult services, but to summarise the current state of the law in this area (for a more detailed overview of the law as it stands as of November 2017 and the decision in D (A Child) [2017], click [here](#))

1. When determining whether a person is confined practitioners still should apply the 'acid test'. The 'acid test' asks you to consider whether the person is under:
 - 'continuous/complete supervision and control',
 - 'is not free to leave,' and
 - that these arrangements will be in place for a 'non-negligible' period of time.
2. Consent for any confinement can be provided from the following for a child or young person under 18:
 - a) by a child with 'Gillick capacity' under the age of 16
 - b) the young person (16+) if they have capacity or
 - c) the parent with 'Parental Responsibility' if;
 - the child (under 16) or young person (16+) lacks 'Gillick capacity' to consent or,
 - the young person (16+) lacks capacity (within the meaning of the MCA), and
 - the parents' consent is within the scope of 'Parental Responsibility' for that person.

NB: even where the child is under a section 20 Children Act arrangement, as long as the family consent and have been informed of the arrangements that amount to a deprivation of liberty, a court authorisation will **not** be required. Where there is dispute regarding the arrangements that amount to a DoL, the Court of Protection or Family Court will still be an option to consider.

Where none of the above applies and consent from the child, young person or person with parental responsibility has not or cannot be obtained these will be the cases that the local authority or CCG have to get authorised by the most appropriate court. This will also be the case where those under 18 who are able to make the relevant decision (have 'Gillick capacity') object to their confinement (for an example of a situation where this could happen refer to the recent judgement in [LB Wandsworth v M & Ors](#)).

3. The requirements for whether the deprivation of liberty is imputable to the state remains the same. If you become aware or ought to be aware of private arrangements that amount to a Deprivation of Liberty, court authorisation will still be required.

Making decisions about people with PWS

In the first instance, the duty of someone working with a person with PWS is to inform and work with the person, as far as possible obtaining their consent to what is necessary to help prevent life threatening obesity. Regarding specific decisions (e.g., a potential move to residential care), the question needs to be asked, "What decision does s/he need to take and does s/he have the capacity to make that decision?"

If, after an assessment, it is believed, on the balance of probability, the person does not have capacity to make the decision in question then the next decision is to determine what is in his/her best interests and what is the least restrictive option? Finally, in very problematic situations, it may be necessary to, at least, consider whether the MHA be used, however, does not resolve the long term issue of managing the food environment. It may, however, be of value if someone with PWS has become seriously depressed or is psychotic and requires temporary treatment in hospital for that reason.

Options for care and treatment of adults with PWS

1. Respect for autonomy - like anyone with obesity - restrictions only with consent.
2. If lacking the relevant capacity to consent - the Mental Capacity Act 2005 - act in his/her best interests and consider whether the restrictions put in place indicate a potential deprivation of liberty and if they do amount to a deprivation (as opposed to a restriction) of liberty apply for authorisation.
3. Other legislation (e.g. Mental Health Act 1983 - amended 2008). The Mental Health Act is more relevant for cases involving severe depression or psychosis, and is less relevant for eating problems.

Option 1 - Consent to dieting and restrictions

- Has been given the relevant information - the risks associated with over-eating and the particular problems for people with PWS;
- Has the capacity to make the decision in question - understands the information and can make and communicate a decision;
- Free to make the decision voluntarily - not making the decision under threats.

Option 2 - Person lacks the capacity to make the relevant decisions

- Assess decision-making capacity - what decisions can be made?
- Best interests and less restrictive options considered
- Identify potential restraints/restrictions
- Is the person deprived of their liberty

Option 3 - Mental Health Legislation - The Mental Health Act, 1983 (MHA)

- This Act also provides the lawful means for insisting that someone has treatment against his/her wishes. The MHA only applies to the treatment of a person's mental disorder (not physical) and very specific criteria have to be met and treatment has to be in hospital.
- Where someone has a serious mental illness (for example severe depression or a psychotic illness) the use of the MHA can be appropriate. It has been used to admit someone with PWS with life-threatening obesity to hospital but its use in such situations is controversial.

The Role of the PWSA UK

PWSA are able to support both families and health and social care professionals in the following ways:

- Challenge decisions based on IQ evidence - if the person does not have an intellectual learning disability (ie has an IQ over 70), in PWS they still have an impairment of the brain or mind.
- If the person with PWS is deemed to have capacity to make a decision, challenge the relevant organisation as to how they are discharging their duty of care towards that person. What will they do if the person's weight becomes life-threatening? Go to the Health Ombudsman to ensure someone takes responsibility.
- Ensure that as far as possible the person with PWS has the relevant information which tells them the consequences of too much independence and overeating.

FAQs

Q: My son fully understands all the implications of the need to restrict food in PWS, and could convince an outsider that he is fully able to make a decision about it, but, given the opportunity, he will always overeat - he is in denial; he thinks he can control that area of his life.

A: This reminds me of the case of Miss MB (not someone with PWS), who needed an urgent Caesarean section but had a phobia of needles. The consequence of not having the section was that her baby would die. In court it was argued that she lacked capacity because of the phobia, which was preventing her making a reasonable judgement. In this case she knew the issues but her fear of needles overwhelmed her. In the end, a similar court case may need to be brought for someone with PWS. A person with PWS may say "I know I can diet" and yet they are so dominated by hunger that to act on that is almost, if not, impossible. However, people with PWS who live in a food-controlled environment are, by and large, much happier than those who don't - the temptation has been taken away from them.

Q: Does the Court of Protection have a role as a forum where options can be discussed where there is disagreement between statutory services, parents, and the person with PWS as to what is in that person's best interests?

A: Yes, the person themselves has an automatic right of appeal over a decision as to his best interests. Others have the right to apply to appeal. The Court has the powers to appoint a Deputy, who could be a relative, to make a decision about a particular situation.

Q: You mentioned that the MCA brings into statute the duty to appoint an advocate under particular circumstances. Can you tell us more about that?

A: An Independent Mental Capacity Advocate (IMCA) must be appointed under specific circumstances - if the person has no family or friends who can speak for him/her and the person concerned lacks the capacity to make the decision in question for him/herself. It only applies to situations where the person is moving accommodation or is faced with serious medical treatment (defined in regulation). IMCAs may also be appointed where family are involved in safeguarding investigations. The role of the IMCA is to make certain that the voice and opinions of the person lacking capacity is heard. The IMCA has to be appointed by the local authority from the local area and be recognised as an IMCA, so it is unlikely it would be possible for a PWSA UK advocate to take on this role. However, the IMCA would be expected to consult with any existing advocate - who may be from the PWSA UK.

Q: What sanctions are in place to remove a person who is putting themselves or others at risk?

A: Where someone lacks the capacity to make a particular decision, the main obligation is to act in that person's best interests. For instance, if they are wandering off and cannot be persuaded otherwise, then gentle restraint may be allowed to guide them back, providing it is proportionate to the risk of harm. Here a distinction might need to be made between what you would like to do in someone's best interest and what is possible. The MCA provides a framework but in practice it can be very difficult and persuasion and long term strategies are often required before a particular problem is resolved.

Q: I am concerned I am considered an over-protective parent and feel that liberal social services and local authorities will take the easy option under the MCA of considering the person with PWS capable, especially where they have an IQ of over 70.

A: Yes, this continues to be a difficult point. One course of action would be to embarrass the LA into thinking through the consequences of their actions - what are they going to do if the person's health deteriorates or the person becomes vulnerable to abuse? You need to point out that this is a genetic disorder. If you feel the LA is not acting in the person's best interests, consider legal action. However, it does all hinge around the issue of capacity and if the LA is of the opinion that your adult child has capacity you may need to seek a further opinion about that. Some people with PWS may have capacity to make relevant decisions - we must be careful not to start with a blanket assumption.

Q: My daughter is currently regarded as being "low criteria" by social services and therefore has few services offered to her. Does the MCA mean that social services will now have to re-write their assessment forms so that the right questions are asked about someone's abilities, rather than just taking the fact that a person can cook and travel independently at face value?

A: Yes, social services will now have to include capacity in their assessments. The uniqueness of PWS should be stressed.

Q: How long should decisions take? Are there any guidelines within the Act?

A: Not really. It is more important that the outcome is in the best interests of the person. The Act is really just a framework for resolving complex ethical dilemmas. I would advise that you make use of the Association if you feel that social services have not properly thought through a decision. There is now no excuse for lack of knowledge as there is plenty of information about PWS on the internet.

Q: How can people assessing capacity make a reasoned decision on the basis of just a couple of interviews with the person with PWS?

A: The person doing the interview must justify their decisions. We have got to start making sure that people take responsibility for their decisions, and realise the pivotal role of capacity. Evidence is crucial. For instance, keeping weight records can show that a person is gaining weight even though they may say they are not. Keep very detailed records and clear evidence that a serious problem exists.

References

1. Hinton, EC; Holland AJ; et al (2005) [Neural representations of hunger and satiety in Prader-Willi Syndrome](#) *International Journal of Obesity*
2. Hawkins, R; Redley, M; Holland AJ (2011) [Duty of care and autonomy: how support workers managed the tension between protecting service users from risk and promoting their independence in a specialist group home](#) *Journal of Intellectual Disability Research*, 55 (9), 873-884

Thank you

This article is compiled from talks given in May 2007 and March 2009 by PWSA UK Patron, Professor Tony Holland, University of Cambridge, with further revisions by him and James Codling, Mental Capacity Act and Deprivation of Liberty Safeguards Training and Development Manager, LGSS.

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