

Mental capacity and the Mental Capacity Act 2005

Introduction

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 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?

Existing legal and ethical contexts for issues surrounding PWS

Human Rights Act

Government legislation and judicial decisions also 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, 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?

International Conventions

- Universal Declaration of Human Rights, United Nations, 1948
- European Convention on Human Rights, Council of Europe, Rome, 1950, Paris, 1952 etc

Valuing People

In addition, there are various UK government policies which need to be considered. Key ones with regard to people with learning disabilities 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)

Common Law

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

- An adult has the right to determine for him/herself what should happen to his/her body - principle of autonomy (self-determination) (Mr C; Ms MB; Ms B - see below).
- In the case of healthcare, consent enables investigation and treatment to lawfully take place.
- Consent requires that a person is adequately informed, has the capacity to make the decision for him/herself, and makes the decision voluntarily.
- Exception to the principle of autonomy - treatment of mental disorder under the Mental Health Act (MHA).

Case law

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 overcame everything else. She had the Caesarean and both she and the child survived.

In addition to the above cases, the case of Mr HL versus the UK (known as the Bournemouth case) was also very important as this case, having gone through the full appeal procedures in the English courts, went to the European Court of Human Rights (ECtHR) where the UK was found at fault. HL was a man with autism and severe learning disabilities who was kept in hospital initially informally against the wishes of his paid carers. The ECtHR found that he had been deprived of his liberty and that there was no clear process for determining such a course of action and no ready means of appeal. It was this case that subsequently led to an amendment of the MCA in order to introduce the Deprivation of Liberty Safeguards (DoLS) in 2009.

The Mental Capacity Act 2005 - General principles

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 substitute decision-making and what principles should apply when making a decision on behalf of another?
- 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 law would also provide the means of challenge when opinions about capacity and/or best interests are disputed. It has taken 10 years of debate, discussion and consultation to finally become an Act of Parliament - the Mental Capacity Act 2005.

Much of the Act is putting into statute existing common law and therefore the principles enshrined in the Act should in fact already be guiding health and social care practice. The MCA is concerned with adults 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.

This 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.

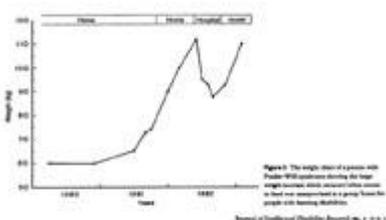
The MCA is very important for those working in health or social care settings, as all those working in a professional or caring capacity with a person found to lack the capacity to make a particular decision, or who is undertaking an act that is required to be undertaken or done, must have regard to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

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.

The capacity of people with PWS to make a decision about food



The diagram shows the first piece of research undertaken by 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 in a hostel again.

Her diet was controlled in her home environment but not when she left home. This scenario has subsequently been repeated many times over with different people with PWS, and perhaps best illustrates why people with PWS should be on a diet and 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.

Consent and diet

The dilemma of what to do to prevent obesity, however, remains and can be extended to other forms of obesity, other than that associated with PWS as well as to the converse, not eating, ie: 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

In PWS the circumstances are different. A two-stage argument could be put forward:

Q: Does the person with PWS have an impairment of brain or mind? (this is a necessary pre-requisite before then determining whether a person might lack the capacity to take a specific decision)

A: Yes, even if they do not have an intellectual learning disability. Brain scans done under research conditions show definite impairment in the brain of people with PWS - ie messages from the stomach to the brain that they have had enough to eat are not getting through. A diagnosis of PWS automatically allows this argument to be put forward.

Q: Can the person make a reasoned decision about whether or not to eat? (this is the second stage in assessing a person's capacity to make a particular decision)

A: No, the analogy here is as with the case of Ms MB (see above), who had the phobia of needles. The drive to eat overwhelms the rational decision-making process. Also the more "chaotic" the environment is, the more capacity to make decisions is decreased in PWS (ie they find it difficult to switch attention from one option or stimulus to another). Decision-making capacity is decision and time specific and someone with PWS may be able to make such decisions in some circumstances but not in others (see below).

Managing the eating disorder in PWS over the lifespan

Children

In childhood, families 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.

Teenagers

During the teenage years, up to age 18, a teenager may have the capacity to make decisions. Even if they clearly are able to make decisions for themselves, parents can still overrule a decision made by their teenager if they decide to refuse treatment.

Adults

In adult life, age 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:

Action by consent

This is probably the best way and can be seen in practice in the case of people with PWS who are living in PWS specific homes - ie, those with PWS 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.

Capacity to make these decisions

It could be argued that the Local Authority have a responsibility to act in the best interests of a person with PWS, if it can be shown that the person concerned lacks the capacity to make decisions about whether to be on a diet or not. This approach might be useful where the adult with PWS does not agree with the decision that he/she should live in a food controlled environment.

For this to be appropriate it would have to be demonstrated that the person with PWS lacked capacity to make such a life style decision and that it was in his/her best interests to live in a specific environment. Experience has shown that to be able to say to a person with PWS that someone else insists that you live in such an environment can be very helpful. It would appear to be very difficult for people with PWS to make that decision for themselves.

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 previously been used to admit someone with PWS with life-threatening obesity to hospital but its use in such situations is controversial.

Where there is no obvious solution to complex problems, such as can occur in the case of people with PWS, an application can be made to the High Court for what has sometimes been termed "a best interest" hearing. Such hearings go, at least initially, to the Court of Protection. In these situations the court can set down specific conditions and determine, for example, where someone should live.

Deprivation of Liberty Safeguards (DoLS)

The Deprivation of Liberty Safeguards apply in England and Wales only and are used in hospitals, residential care and, due to a recent Court ruling, also in supported living. There are six assessments which 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 is called the relevant person's representative and will usually be a family member or friend.

Other safeguards include rights to challenge 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

www.scie.org.uk/publications/ataglance/ataglance43.asp

Mental Capacity Act - Determining capacity in 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.

Assessment of capacity

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

- There must be evidence of a disability that might affect capacity. As argued above it would be reasonable to argue that a diagnosis of PWS is evidence in itself.
- A functional approach must 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).

Lack of capacity

To prove a lack of capacity, it does not matter whether the impairment or disturbance is permanent or temporary; it should not be solely judged on age, appearance or behaviour, and should be decided on a balance of probabilities. The latter is a lower level of proof than that required in a criminal court - "beyond reasonable doubt".

Inability to make decisions

Section 3(1) of the 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).

If the MCA was to be used to determine that a person with PWS had to live in a food restrictive environment it would have to be demonstrated that the person concerned lacked the capacity to make a decision regarding food intake. Whilst people with PWS may understand the issues, I would argue that some people with PWS 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.

Decision-making capacity

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. In assessing that person's capacity, you then ask them to explain these particular issues that they have been told about.

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

Best interests

If it is decided that someone lacks the capacity to make a particular decision that is required to be made 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.

The Role of the PWSA UK

- 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 organisation as to their duty of care. What will they do if the person's weight becomes life-threatening? Go 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.

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 it is believed the person does not have capacity, then the next decision is to determine what is in his/her best interest and what is the least restrictive option? Finally, in very problematic situations, it may be necessary to at least to consider whether the MHA be used. However, such legislation 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 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.
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 - Doubts about the person's capacity to make the relevant decisions

- Assess decision-making capacity - what decisions can be made?
- Understand
- Retain
- Weigh-up
- Communicate
- Best interests

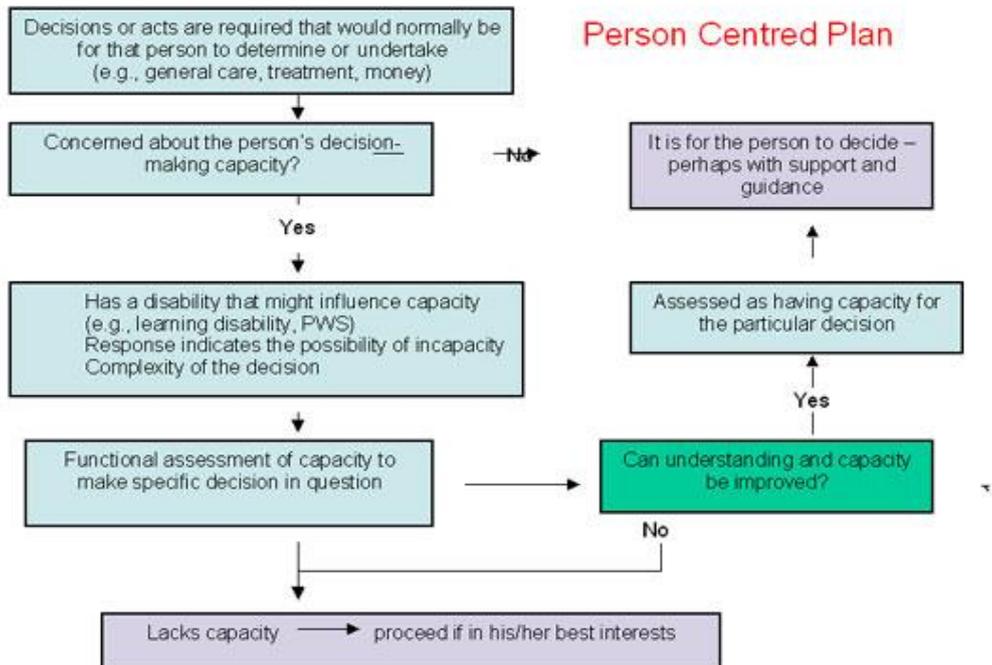
Option 3 - Mental Health Legislation

- The MHA is to enable the assessment and treatment of a person's mental disorder in the absence of consent.
- It is a balance between the rights of an adult to self-determination and the need for treatment for a mental disorder.
- It is not to enable the treatment of a physical illness in the absence of consent.

Examining the issues with regard to people with PWS

The following questions should be answered:

- 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?
- Should other law be used?



Ethics and PWS

As stated before, there are no laws which 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 such that the liberty of a person with PWS should be limited in order to prevent severe obesity?

Responsibilities of carers and the Local Authority

What responsibility do carers 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. 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.

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?

A: Yes, the person themselves has an automatic right of appeal over a decision as to his best interest. 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 care or protection of vulnerable adult (POVA) proceedings. 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 maybe 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 - 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 President, Professor Tony Holland, University of Cambridge, and reprinted with his permission.