

SD-08

POLICY AND PROCEDURE

Capacity and Consent of Service Users

Approved by: *Pat O'Sh*

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CARRIGLEA CAIRDE SERVICES

GUIDELINES

Title: CAPACITY AND CONSENT OF SERVICE USERS

1.0 Scope

- 1.1 The procedure for ensuring that service users consent is obtained and the procedure for assessing service users' capacity to give informed consent.

2.0 Aims and Values

- 2.1 To ensure that service users are consulted with in relation to every aspect of their lives and that their decisions are respected in cases where they have the capacity to make informed decisions.
- 2.2 To help service users to understand the possible consequences of their decisions and help them to make informed choices.
- 2.3 To ensure that specific decisions made on behalf of a service user where it has been determined that they lack capacity, are in the best interest of that person.
- 2.4 To comply with legal obligations in relation to service user capacity and consent.

3.0 Contents

- 6.0 General Guidelines
- 7.0 Informed Decision Making
- 8.0 Medical Consent
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- 10.0 When is Consent Required?
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- 13.0 How and When should information be offered?
- 14.0 What information about risks and side effects of an intervention should be provided?
- 15.0 Is the person's decision made voluntarily?
- 16.0 Has the person the capacity to make the decision?
- 17.0 What should be done if somebody lacks capacity to make a decision?
- 18.0 How should consent be documented?
- 19.0 When should consent be sought?
- 20.0 What if a person refuses to give consent?
- 21.0 Can consent be withdrawn?
- 22.0 Advance refusal of treatment
- 23.0 Assisted Decision Making (Capacity) Act, 2015

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CARRIGLEA CAIRDE SERVICES

GUIDELINES

4.0 Referenced Documents

SD-34 Personal Development, Relationships and Sexuality
SD-39 Residential/Respite Service Users Finances and Service User Accounts
SD-43 Safeguarding Vulnerable Persons at Risk of Abuse
SD-42 Resuscitation
C4-39 Money Management Competency Assessment
 Person Centred Plan
 Service User's Daily Report
 HSE National Consent Policy

5.0 Responsibilities

5.1 Management and all staff.

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6.0 GENERAL GUIDELINES

- 6.1 Service users have a right to be treated with dignity and respect and to live full and enriching lives in accordance with their personal choice as documented in their Person Centred Plan and supported when necessary or appropriate, by their chosen circle of support.
- 6.2 Managers and staff in the course of their everyday work will be involved in decision making that affects the lives of service users (this includes anything from helping people dressing to medical procedures). Best practice should always be used and the process leading to a decision for or by a service user should be transparent so that it can be clearly explained.
- 6.3 It is vital that managers and staff can describe the evidence drawn upon and the thinking that has led to the reason for making a decision in relation to a service user. It should be possible to satisfactorily demonstrate the reason for a decision to all stakeholders involved. This should be documented in the *Service User Daily Report Record* or relevant care or support plan.
- 6.4 Service users are encouraged to exercise choice and control across a range of daily activities. Empowering service users by involving them in decision-making is fundamental to good practice.
- 6.5 With regard to everyday events and activities, every effort must be made to explain to service users the balance between their safety/wellbeing and reasonable risks they may wish to take.
- 6.6 Service users understanding of giving consent should be developed through personal development programmes. However, informed consent may not be a realistic option for many individuals who will need ongoing protection and support.
- 6.7 The free giving of consent implies that the individual has the understanding and the ability to refuse should he/she so wish. This cannot happen unless he/she has good assertiveness skills which should be developed and encouraged throughout the person's daily life.
- 6.8 Carriglea Cáirde Services is committed to at all times, act in accordance with legislation and current best practice guidelines when dealing with issues related to service users capacity to give consent.
- 6.9 Separate guidelines are set out in relation to service users consent to sexual relationships (*See Personal Development, Relationships and Sexuality*).
- 6.10 **Detailed guidelines in relation to consent are available in the HSE National Consent Policy which is available on the HSE website and in the Booklets Box in all Carriglea Cáirde Services day and residential areas.**

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7.0 INFORMED DECISION MAKING

- 7.1 Staff should make every effort to build service users capacity to make decisions for themselves and support them to make decisions for themselves. Information should be presented to service users using communication methods which aid their understanding, to enable them to make informed decisions.
- 7.2 Each person enjoys legal capacity on an equal basis with others in all aspects of life. A service user should be considered to have the ability to give consent unless there are specific reasons to be concerned that the individual may not be able to do so. In such instances, the individual should be assessed on a specific issue with regard to their ability to give informed consent on that particular issue. This assessment should be conducted by a best interest panel comprising of people who know the individual well, an advocate (who may be a family member) and a relevant professional from the multi-disciplinary team.
- 7.3 The fact that a service user has been found to lack capacity to make a decision on a particular occasion, does not mean that they lack capacity to make any decisions at all, or that they will not be able to make similar or other decisions in the future.
- 7.4 Service users should be facilitated to access citizens' information, independent advocacy services or an advocate of their choice to assist them in making decisions, if they so wish.
- 7.5 Any use of threats to induce consent such as withdrawal of privileges is not acceptable.
- 7.6 When a service user has difficulty in communicating his/her wishes or in making informed decisions, staff should work in close collaboration with the person's representative to help ascertain the person's wishes.
- 7.7 Service users who lack capacity to make decisions for themselves should not be put at risk or exploited.
- 7.8 Procedures regarding service users' capacity to make decisions in relation to their finances are dealt with in the *Residential/Respite Service Users Finances and Service User Accounts Policy*. Competency is assessed by completing the *Money Management Competency Assessment*. A finance care plan may be drawn up.
- 7.9 Individual consent forms are provided by hospitals and dental clinics for service users who are to undergo medical or dental procedures.
- 7.10 When it is deemed necessary to take a decision on behalf of a service user, such a decision should always be based on the best understanding of the person's will and preferences.

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7 11 Where it is established that a vulnerable person does not have the capacity to make decisions and/or protect themselves, professionals involved must take appropriate steps to protect the person and follow the 'in the best interest' principle. Where any allegations are received or where staff have any matters of concern they must always act in the best interest of the service user to protect him/her and follow Carriglea Cáirde Services policy on *Safeguarding Vulnerable Persons at Risk of Abuse*.

8.0 MEDICAL CONSENT

- 8.1 In no circumstances should any member of staff give formal consent for medical treatment of a service user e.g. general anaesthetic or any medical procedure. If a member of staff is asked to give such consent they should immediately inform the senior staff on duty who should then consult with the person's family or the Chief Executive, as appropriate.
- 8.2 A family member cannot legally give or refuse consent on behalf of an adult service user. However, it is appropriate to consult with close family members to ascertain what they believe to be in the best interest of the service user.
- 8.3 Until such time as a ward-ship is formally terminated and an alternative arrangement put in place under the Assisted Decision-Making Act, 2015, the consent of the Wards of Court office must be obtained before a major medical procedure for any service user who is a Ward of Court.
- 8.4 In the case of a medical emergency, if a patient has made no decision, and is in no position to make one, doctors have both the right and duty to treat in accordance with what, in their clinical judgement, they consider to be the patient's best interests.
- 8.5 When a member of staff is aware that a service user is unable to request treatment or speak for themselves in the diagnosis of a medical condition which may affect the treatment given, they should inform the medical practitioner of all relevant information.
- 8.6 The following is the procedure in Carriglea Cáirde Services:
 Consent is requested verbally from the service user prior to any treatment. Where written consent is required, it is discussed with the service user and they can sign consent where applicable. The need for consent is also discussed with the following:
- Family – Next of kin
 - Relevant professional e.g. GP/dentist/psychiatrist as appropriate
 - The staff team who work directly with the service user
 - The Senior Services Manager
 - The Chief Executive, in situations where there is no next of kin.
 - Until such time as the ward-ship is formally terminated and an alternative arrangement put in place, the approval of the Wards of Court office is required for surgery or any major procedure in the case of a service user who is a Ward of Court.

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8.7 With regard to decisions pertaining to resuscitation, see policy and procedure on *Resuscitation*.

9.0 HSE Guidelines on Consent for Health and Social Care professionals.

9.1 The following points are taken from the HSE document '*Consent: A guide for health and social care professionals*' (issued in May, 2013) which applies to adults. Carriglea Cáirde Services adopts these guidelines and staff are required to follow the principles set out in points 10.0 to 22.0 below

10.0 When is Consent Required?

10.1 The need for consent, and the application of the general principles in this policy, extends to all interventions conducted by or on behalf of the HSE on service users in all locations. Thus, it includes social care as well as health care interventions and applies to those receiving care and treatment in hospitals, in the community and in residential care settings. It includes, for example:

- Physical examination
- Provision of intimate personal care
- Blood tests
- Radiological examinations
- Surgical procedures
- Anaesthetic procedures
- Chemotherapy and radiotherapy treatment
- Administration of medications
- Use of blood products
- Clinical photography and video/audio recording
- Assessment of need for health or social care
- Provision of social care
- Psychological interventions
- Sharing of personal information
- Provision of day or residential care
- Participation in social or educational activities as part of social care provision

10.2 The amount of information provided and the degree of discussion needed to obtain valid consent, will vary with the particular situation. For example, a minor risk-free procedure, such as changing a dressing, may require only a brief explanation and a warning about possible discomfort. On the other hand, extensive discussion will be required for a major decision involving significant risks, such as whether or not to have surgery

11.0 What is valid consent?

11.1 Consent is the giving of permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication about the proposed

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intervention. Seeking consent is part of good practice in communication and decision-making and should usually occur as an on-going process rather than a once-off event.

11.2 For consent to be valid, the person must:

- have received sufficient information in a comprehensible manner about the nature, purpose, benefits and risks of an intervention or service;
- be acting voluntary (that is, not under pressure or duress from anyone); or
- have the mental capacity (be 'competent') to make the particular decision at that time.

12.0 What information do people need?

12.1 The amount of information to be provided about an intervention will depend on the urgency, complexity, nature and level of risk associated with the intervention and on the preferences of the person. Many decisions require the person to balance potential risks and benefits of the intervention and, in order to do so, he or she will need adequate information about:

- Their diagnosis and prognosis
- Options for treating or managing the condition, including the option not to treat
- The purpose of any proposed intervention and what it will involve
- The potential benefits, risks and the likelihood of success of a proposed intervention, as well as that of any available alternative.

12.2 When someone is admitted to residential care, there is a requirement to understand the nature and multiplicity of interventions that might be provided while a resident.

13.0 How and when should information be offered?

13.1 It is essential that the relevant information is provided in a form that the particular person can understand. This is particularly important with those who may have difficulty making decisions including those with communication difficulties, intellectual disability or cognitive impairment. Helpful measures to support the person's ability to understand may include offering information in a variety of forms depending on the person's needs (for example if they have any sensory impairment) and preferences. Use of simple, clear and concise language and avoidance of jargon and medical terminology are also important.

13.2 The manner in which information is presented is also important. You should ensure that information is provided in a respectful way, for example by finding an appropriate, private place to discuss confidential matters. You should also ensure that people have the time and support they need to make their decision.

14.0 What information about risks and side effects of an intervention should be provided?

14.1 In providing medical care, a general rule is to provide information about risks that a reasonable person in the patient's situation would expect to be told or would consider significant. This is in line with ethical and professional standards as well as the legal standard applied by the Irish courts. Factors such as someone's occupation or lifestyle may influence those risks that they consider significant or particularly undesirable. For example, for a person used to living independently who values being on

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their own, communal living might be very challenging, and the potential disadvantages should be raised if admission to residential care is under consideration.

In general, information about risks includes the likelihood of:

- side effects or complications of an intervention,
- failure of an intervention to achieve the desired aim, and
- the risks associated with taking no action or with taking an alternative approach

- 14.2 Common, even if minor, side effects such as transient nausea or discomfort, should be disclosed as should rare but serious adverse outcomes. The latter include death, permanent disability (such as paralysis or blindness), permanent disfigurement and chronic pain.
- 14.3 In an emergency life-threatening situation, treatment that is immediately necessary to save the life or preserve the health of the person should be administered even if there is no time for the health care professionals to provide a full explanation or if the person is unable to provide consent.
- 14.4 Unfortunately health and social care often involves difficult or worrying information or decisions, and it is understandable that health and social care professionals or family or friends may wish to shield a service user from anxiety. However, it is essential that a service user receives sufficient information to know what is involved in an intervention or decision and to be able to consent or withhold consent. The fact that somebody might be upset or refuse treatment or services as a result of receiving information as part of the consent process is not a valid reason for withholding information that they need or are entitled to know.
- 14.5 It is often helpful in these circumstances to ask the service user if they would like a relative, friend or advocate to be present at the consultation as a support and to spread out the time over which information is given to better enable someone to come to terms with it. It is also important that information about risk should be given in a balanced way: a 1 in 100 risk of a complication also means that 99 out of 100 patients will not experience that complication.

15.0 Is the person’s decision made voluntarily?

- 15.1 It is very important to ensure that the person’s decision is their own and that they understand that they have a choice. Health and social care professionals have a role to play in discussing treatment and care options and may have a recommendation to make or may need to point out the likely consequences of choices the person may make. Nevertheless, care should be taken that people do not feel forced into making a particular decision.
- 15.2 People may also be subject to pressure from family and friends to accept or reject a particular intervention. Again, care should be taken to ensure that the person ultimately makes his or her own decision, for example by discussing treatment and care options with the person in the absence of family or friends if the person is comfortable with that.

16.0 Has the person the capacity to make the decision?

- 16.1 Adults are always presumed to have capacity to make healthcare decisions, unless the opposite has been demonstrated.
- 16.2 Capacity should be judged in relation to the particular decision to be made, at the time it is to be made. This is sometimes called the “functional approach”, and recognises that, some people may

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have capacity to consent to some interventions but not to others. The fact that a person has been found to lack capacity to make a decision on a particular occasion does not mean that they lack capacity to make any decisions at all, or that they will not be able to make similar or other decisions in the future.

16.3 Capacity to consent requires that:

- The person understands in broad terms the nature of the decision to be made;
- The person has sufficient understanding of the main benefits and risks of an intervention and relevant alternative options after these have been explained to them in a manner and in a language appropriate to their individual needs;
- The person understands the relevance of the decision and is able to retain this knowledge long enough to make a voluntary choice
- Adults are always presumed to have capacity to make healthcare decisions, unless the opposite has been demonstrated. It must not be assumed that somebody lacks capacity to make a decision solely because of their age, disability, appearance, behaviour, medical condition (including intellectual disability, mental illness, dementia or scores on tests of cognitive function).
- Capacity should not be confused with the reasonableness or wisdom of the person's decision. People are entitled to make a decision based on their own religious belief or value system, even if that decision is perceived by others to be irrational, as long as they understand what is entailed in their decision.
- People who lack capacity to make a decision will nevertheless very often be able to express a preference to receive or forgo an intervention. Even in the presence of incapacity, the expressed view of the person carries great weight and, except in emergencies, it may often be impractical or undesirable to try to impose care, treatment or investigation on someone who resists it.
- Legal advice should be sought in respect of refusal by a person lacking capacity of any major intervention including surgery, prolonged detention or other restrictions on liberty
- Health care professionals have a duty to maximise capacity This requires that efforts must be made to support individuals in making decisions for themselves where this is possible.

17.0 **What should be done if somebody lacks capacity to make a decision?**

17.1 In making decisions for those who lack capacity, you should determine what is in their best interests. Factors that you should take into account include:

- Evidence of the person's previously expressed preferences, wishes and beliefs
- Whether the lack of capacity is temporary or permanent
- Which options for treatment or care would provide overall clinical benefit for the person
- Which options, including the option not to treat or provide care, would be least restrictive of the person's future choices
- The current views of the person if ascertainable

17.2 The views of those who have a close, on-going, personal relationship with the person such as family or friends are often helpful in the discussion and decision-making process for those who lack capacity particularly with regard to providing greater insight into the person's previously expressed views and preferences.

17.3 However, no other person such as a family member, friend or carer (and no organisation) can give or refuse consent to a health or social care service on behalf of an adult who lacks capacity to consent unless they have formal legal authority to do so. The designation of a family member as 'next-of-kin' does not confer any legal decision-making authority In the absence of a person with legal authority

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to make decisions on behalf of the service user, the health and social care professional must make the relevant decision on the basis of his or her assessment of the best interests of the service user.

17.4 In emergency situations where a patient is deemed to lack capacity and there is no valid advance refusal of treatment, you should act in the best interests of the patient bearing in mind the principles outlined above. This usually means providing any treatment immediately necessary to save the life or to prevent a serious deterioration on the condition of the patient. While it is good practise to inform those close to the patient, nobody else can consent on behalf of the patient in this situation.

17.5 The person seeking consent should have sufficient knowledge of the intervention and be able to convey that knowledge effectively

18.0 How should consent be documented?

18.1 It is essential for those who provide health and social care to document clearly the person's agreement to the intervention and the discussions that led up to that agreement particularly if:

- The intervention is invasive, complex or involves significant risks
- There may be significant consequences for the service user's employment, or social or personal life
- Providing clinical care is not the primary purpose of the intervention e.g. clinical photographs or video clip to be used for teaching purposes or blood testing following needle stick injury to staff
- The intervention is innovative or experimental.

18.2 The service user's agreement can be documented by their signature (or mark if unable to write) on a consent form or through documenting in their notes that they have given verbal consent.

18.3 While it is important to document consent adequately, the process and quality of communication are of equal importance.

18.4 A signature on a form is evidence that a process of communication has occurred and that the service user agrees to an intervention. It is, however, not proof that an adequate process of communication has occurred or that the consent is valid. On the other hand, if a person has given valid verbal consent, the fact that they are unable to sign the form is no bar to treatment. Thus, while it is important to document consent adequately, the process and quality of communication is of equal importance.

19.0 When should consent be sought?

19.1 For a major intervention such as a surgical procedure, it is good practise where possible to seek the patient's consent to the proposed procedure well in advance, for example in the out-patient clinic, when there is time to respond to the patient's questions and provide adequate information.

20.0 What if a person refuses to give their consent?

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20.1 If an adult with capacity to make an informed decision makes a voluntary and appropriately informed decision to refuse a proposed treatment or service, this decision must be respected, even where the decision may result in his or her death. In such cases it is particularly important to accurately document the discussions with the patient or service user, including the procedure that has been offered, their decision to decline and the fact that the implications of this decision have been fully outlined. If you are unsure about the service user's capacity to make a decision, the guidance provided earlier should be followed. However, there are some circumstances in which a valid refusal of consent raises complex legal and ethical issues and it may be advisable to seek legal advice:

- Refusal of treatment in pregnancy where the refusal creates a risk to the life of the foetus
- Refusal of isolation for infectious disease
- Refusal of the taking of blood and urine samples for the purposes of Garda investigations into driving under the influence of alcohol and/or drugs.

20.2 Patients admitted involuntarily under the Mental Health Act 2001 have the same right as other patients to refuse treatment for all conditions except for treatment for a mental disorder, which must be proved in accordance with the requirements of the Mental Health Act 2001. If in doubt about whether treatment can be categorised as treatment for a mental disorder, legal advice should be sought.

21.0 Can consent be withdrawn?

21.1 A person with capacity is entitled to withdraw consent at any time, including after signing a consent form or even during the performance of a procedure. Where a service user does object during a treatment or service, it is good practise for the practitioner, unless this would genuinely put the life of the service user at risk, to stop the procedure, establish the service user's concerns, and explain the consequences of not completing the procedure. If the service user confirms that they wish to withdraw consent, this should be respected and the episode documented.

22.0 Advance refusal of treatment

22.1 Sometimes service users may wish to plan for their medical treatment in the event of future incapacity, including advance refusal of medical treatment. There is no Irish legislation confirming the enforceability of such advance refusals. However, such an advance plan should be respected on condition that:

- The decision was an informed choice, according to the principles discussed earlier
- The decision specifically covers the situation that has arisen
- There is no evidence that the service user has changed their mind since the advance plan was made.

If there is reasonable doubt about the existence of an advance treatment plan, the service user's capacity at the time of making the treatment plan or whether it still applies in the present circumstances, treatment decisions should be made according to the principles discussed earlier. Legal advice may be advisable in such circumstance if the decision will have a significant impact on the service user's health.

Note: Further information pertaining to capacity and consent are set out in the HSE web-site: National Guidelines on Accessible Health and Social Care Services (June, 2016).

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23.0 ASSISTED DECISION-MAKING (CAPACITY) ACT 2015

23.1 The Assisted Decision-making (Capacity) Act governs the law in relation to adults who are experiencing difficulties with decision making, including people with an intellectual disability

23.2 Under the Assisted Decision Making process the following options are available:

- A person can appoint a Decision Making Assistant typically a family member or friend through a formal decision-making assistance agreement to support him/her to access information or to understand, make or express decisions. The decision making assistant will also follow up to ensure that the decision is implemented
- A person can appoint a Co-Decision Maker, typically a family member or friend who has a relationship of trust, to make decisions jointly with them. This agreement must be registered with the Director of the Decision Support Service and must be reviewed regularly
- For people who are unable to make decisions, even with help, the Circuit court may appoint a Decision-Making Representative. The decision making representative can make decisions on behalf of the person, but must abide by guiding principles which are in place to safeguard the autonomy and dignity of the person. The decision-making representative must report annual to the Director of the Decision Support Services.

23.3 Further information on Assisted Decision Making is available from the Citizens Information Board.

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