Module 5

Supporting and protecting people's rights

Module 5: Supporting and protecting people's rights

Introduction

People with dementia, their families and carers have the same rights as everyone else in society and we need to empower, enable and support them to exercise their rights throughout their dementia journey. In this module we will explore what rights are and our duty to ensure the dignity, civil and legal rights of people with dementia are respected, and they are given the level of assistance they want and need to participate in decisions that affect their lives. We will look at how legislation, policy and guidance in Scotland can be used to protect the rights of people with dementia.

Learning Outcomes

By the end of this module you should be able to:

1. Understand and apply the **Charter of Rights for People with Dementia and their Carers in Scotland** to inform and develop your practice.
2. Understand the principles and provisions of legislation in place to protect people with dementia, and their families/carers rights and choices, and how this should inform your practice.
3. Understand the principles and provisions of policy and legislation that are in place to provide people with dementia and their families/carers with safeguards and protection, and how this should inform your practice.
4. Understand the principles of capacity and consent and how this applies to your role to inform and develop your practice.
5. Contribute to the assessment and support of people with dementia who may be experiencing neglect, harm or abuse.
6. Examine the concepts of risk and risk enablement in relation to your role in supporting people with dementia.

What are rights?

Rights can mean different things to different people, and in different cultures and countries. In Scotland and the UK rights are something people expect to have so that they can experience an acceptable quality of life. They are not about privileges or being allowed to do something – they are a 'given' and are generally thought of as protected. We would expect that people with dementia, their families and carers would experience these same rights. Unfortunately people with dementia can experience stigma, abuse, discrimination, mistreatment and a lack of access to appropriate services to meet their needs.

The rights of their families and carers are also sometimes ignored, and they may not be supported or treated as equal partners in supporting and caring for the person with dementia.

However, legislation in Scotland enables all workers to have a role in ensuring people's rights can be better protected to maximise their potential for a good quality of life.

Activity

- What is your own view of rights?
- Do you know what your rights are?

Record your answers here:

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The Charter of Rights for People with Dementia and their Carers in Scotland

In 2009 a Cross Party Group on Alzheimer's in the Scottish Parliament published **The Charter of Rights for People with dementia and their Carers in Scotland**. The Charter reflects protection laws that already exist in Scotland and uses these to focus on the rights specific to people with dementia.

It describes how people with dementia, their families and carers can be empowered and supported to exercise these rights at every stage of their journey, and wherever they live in Scotland.

The table below outlines a summary of the Charter of Rights.

Summary of the Charter of Rights

Participation

The person with dementia and their family and carers have the right to:

- Information in a format which is accessible to them and the support they need to exercise their right to participate in decisions affecting them.
- Live as independently as possible with access to recreational, leisure and cultural life in their community.
- Full participation in all elements of care assessment, planning, support and treatment decisions, including advance planning.
- Participate in creation and implementation of policies affecting their well-being and the exercise of their human rights.

Accountability

The person with dementia and their family and carers have the right to:

- Enjoy human rights and fundamental freedoms in every part of their lives, including full respect for their dignity, beliefs, individual circumstances and privacy.

All organisations and individuals responsible for the care and treatment of people with dementia should be held accountable for the respect, protection and fulfilment of the person's human rights and adequate steps should be taken to ensure this happens.

Legality

The person with dementia and their family and carers have the right to have their human rights respected, protected and fulfilled. In addition they have the right to:

- Live in dignity and security, free from exploitation, violence and physical, mental or sexual abuse.
- Economical, social and cultural rights including an adequate standard of living, social protection and the highest attainable standard of physical and mental health.
- Information to participate in decision making, and where rights are not observed, the right to seek remedy through effective complaint and appeal procedures.
- The same civil and legal rights as everyone else and where someone lacks capacity anyone acting for them must have regard for the principles and provisions of the Adults with Incapacity (Scotland) Act 2000.

Summary of the Charter of Rights (continued)

Non-discrimination and equality

The person with dementia and their family and carers have the right to:

- Be free from discrimination based on any grounds such as age, disability, gender, race, sexual orientation, and religious beliefs, social or other status.

Empowerment

The person with dementia has the right to:

- Access appropriate levels of care providing protection, rehabilitation and encouragement.
- Help to attain and maintain maximum independence, physical, mental, social and vocational ability and full inclusion and participation in all aspects of life.
- Access social and legal services to enhance their autonomy, protection and care.
- Services provided by professionals and staff with appropriate training on dementia and human rights.
- The person with dementia, their family and carers have the right to access opportunities for community education and lifelong learning.

Activity

Are any of these rights similar to your list?

If there are differences why do you think this might be?

Record your answers here:

How the law in Scotland helps to protect people's rights

Legislation aimed at protecting rights tends to be developed as a result of concerns that individuals and particular groups of people are at greater risk of having their rights denied, such as: people with mental health problems; people with a learning disability; older people and people with dementia. However, we cannot assume that because a person has a particular need, health issue, or disability, that they cannot exercise their rights and choices. The law in Scotland assumes that every adult has a right to, and is capable of making all decisions affecting their lives. Deciding someone is not able to make decisions or protect their own interest can be extremely complex.

In Scotland legislation that may be used to protect the rights of people with dementia include:

- Human Rights Act, 1998.
- Adults with Incapacity (Scotland) Act, 2000.
- Mental Health (Care and Treatment) (Scotland) Act, 2003.
- Adult Support and Protection (Scotland) Act, 2007.
- Equality Act, 2010.

These laws on their own do not protect people but they do create a framework in which organisations and individual workers are legally required to provide services to a certain standard. As changes and amendments to legislation may occur over time it is important to check the Scottish Government website.

Each Act can be used on its own to protect a person, or they can be used together when this is needed. One of the key elements of these laws is that they all are based on 'principles' that must be followed when used to protect people.

Activity

Take a few minutes to consider what 'principles' mean to you and make a list below:

Record your answers here:

Principles are basic moral rules that we use as the basis for all our judgements and actions. They can help us to think about our own attitudes and prejudices. In Adult Protection laws, principles are general rules that guide the way we work with people and make decisions when we use each Act. It is important that you know the principles of each Act and can use them to influence your practice.

The following table describes the shared principles of the 3 pieces of Adult Protection legislation in Scotland which we need to take account of before we consider any intervention, action, or treatment.

Adults with Incapacity Act 2000	Mental Health Act 2003	Adult Support and Protection Act 2007
Benefit: The intervention must enable the person to do something which they could be reasonably expected to do if their capacity was not impaired.	**Benefit:** Any intervention under the Act should be likely to produce a benefit for the person which cannot reasonably be achieved other than by the intervention.	**Benefit:** The intervention must enable the person in some way.
Least restrictive option: The intervention must balance risk versus protection and be the least restrictive on the freedom of the person	**Least restrictive alternative:** People should be provided with any necessary care, treatment and support, in the least invasive manner and in the least restrictive manner, and in an environment compatible with the delivery of safe and effective care - taking account, where appropriate, the views and safety of relevant others.	**Least restrictive option:** The intervention must balance risk versus protection and be the least restrictive on the freedom of the person.
Past and present wishes of the adult: This needs to take into account if it is something the person would have chosen to do in the past or in their present circumstances.	**Participation:** People should be fully involved, to the extent permitted by their individual capacity, in all aspects of their assessment, care, treatment and support. Account should be taken of their past and present wishes, so far as they can be ascertained.	**Respect for adult's past and present wishes:** needs to take into account if it is something the person would have chosen to do in the past or in their present circumstances.
Views of relevant others: Must be taken account of including family, carers and others appointed to make decisions on person's behalf.	**Respect for carers:** Those who provide care on an informal basis should receive respect for their role and experience, receive appropriate information and advice, and have their views and needs taken into account.	**Consider views of others:** These must be taken account of including family carers and others appointed to make decisions on person's behalf.

Adults with Incapacity Act 2000 (continued...)	Mental Health Act 2003 (continued...)	Adult Support and Protection Act 2007 (continued...)
Encourage the adult to act: By using their existing skills and developing new skills.	**Informal care:** Wherever possible care, treatment and support should be provided to people without recourse to compulsion.	**Encourage the adult to participate:** Providing information and support to enable them to do so.
	Non discrimination: People with mental health problems should retain the same rights and entitlements as those with other health problems.	**Non discrimination:** The adult should not be treated less favourably than another adult.
	Respect for diversity: People should receive care, treatment and support in a manner that accords respect for their individual qualities, abilities and diverse backgrounds, and properly takes into account their age; gender; sexual orientation; ethnic group and social, cultural and religious/ belief background.	**Respect for diversity:** The adult's abilities, background and characteristics must be taken into consideration in any intervention.

Please be aware that the Mental Health (Care and Treatment) (Scotland) Act, 2003 contains additional principles that we have not listed here.

We can see that that many of the principles are the same across all 3 Acts - particularly the need to take account of: benefit; the least restrictive option; people's past and present wishes; the views of others, and encouraging the person to participate. These are also in line with the Charter of Rights for People with Dementia and their Carers in Scotland, and the Human Rights Act which you will read about a little later in this module.

Activity

Consider the principle of ‘benefit’.

Read Hugh’s story. Do you think David and Nicola are considering the benefit of their actions for Hugh?

> A brother and sister, David and Nicola, both support their dad Hugh, who is at an advanced stage of his dementia journey. They have been arguing about how much of his money each of them spend. The tension is coming to a head, and David accuses Nicola of ‘abusing’ Dad’s finances by purchasing a television as a birthday present from Hugh to her daughter.
>
> What ‘benefit’ is there for Hugh in buying a birthday present for his grandchild?

Record your answer here:

There is no absolute right answer, but if Hugh had always bought birthday presents for his grandchild and it is known that he did this as part of a loving and sharing relationship then it would be acceptable. However, the amount spent would also need to be in keeping with previous exchange of gifts, and reflect any change to Hugh’s income that may impact on his overall financial circumstances.

Now read the next scenario.

> David lives in the South of England and has decided he wants to buy a car so that he can increase his visits to Hugh from twice a year to four times a year.

Would this be of benefit to Hugh?

Record your answer here:

It would be very difficult to justify this expenditure when the benefit may be more to the relative than the person with dementia.

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The Human Rights Act, 1998

The Human Rights Act supports and strengthens the other Acts. It came into force in October 2000 and has made rights from the European Convention on Human Rights enforceable in British Courts.

Human rights are rights and freedoms that everyone is entitled to. The Human Rights Act originated from concerns for people being denied their basic rights during the Second World War and provides a common understanding of what everyone's rights are.

There are 16 basic rights that apply in Scottish law, all of which have been taken from the European Convention on Human Rights.
The 16 basic rights cover a range of areas including freedom from inhumane treatment, to everyday things like respect for privacy and family life.

The convention recognises that while rights cannot be taken away except in extreme circumstances, most are balanced against the rights of other people such the right to respect for private life and family, while others are considered absolute such as the right to life.

The principles which underpin the Human Rights Act are:

- Equality
- Respect
- Dignity
- Fairness
- Autonomy

Rather than detailing all 16 Rights, here are some practice examples adapted from the Charter of Rights for People with Dementia and their Carers which relate directly to people with dementia, and will help you to recognise these in your practice and workplace.

Examples of human rights that may be disregarded for people with dementia in practice

The right not to be treated in an inhuman or degrading way

- Leaving a person in soiled or unchanged clothing or bedding.
- Leaving food for the person, without offering help when they are unable to eat or drink without assistance.
- Speaking about people in a derogatory way, or in a way that labels or stereotypes them, e.g. 'walkers', 'feeders', 'wanderers'.

The right to respect for private and family life, home and correspondence

- Separation from families and other key people the person has relationships with, due to a hospital or care home admission.
- Not receiving support to participate in activities meaningful to the person.
- Staff working with people in different settings such as care homes or hospitals, controlling people's mail and phone calls.

The right to freedom or liberty

- Detaining a person in a hospital or care home who lacks capacity to consent to admission, and without using legal process.
- Delays in discharging people detained under Mental Health legislation.
- Excessive and inappropriate use of restraint in all care settings, including the person's home.

Examples of human rights that may be disregarded for people with dementia in practice (continued)

The right to a fair trial

This does not just apply to criminal proceedings but to a broad range of areas where a person's civil rights or responsibilities are influenced:

- The person's complaint is not investigated by an organisation.
- The person is not made aware of the right to complain and not given information about the procedure to enable them to make a complaint.

The right not to be discriminated against

Discrimination can be direct or indirect. This right does not apply on its own. A person can only use the Human Rights Act to argue discrimination if another human right is breached;

- A person is not given access to medical treatment or community care services, based on age, disability, gender or ethnic origin or because they have dementia.
- A person with dementia is not offered physiotherapy treatment in the belief that they will not be able to follow exercise instructions.
- Information or options are given in a way that is inaccessible to the person.
- Not offering food to take account of a person's cultural differences such as kosher or halal foods.

Reflection

Reflect on your own work environment and practices in relation to the examples of human rights that may be disregarded for people with dementia.

- Can you identify any risks, or examples, that might suggest the people with dementia you are working with may have their human rights disregarded?
- What changes, or improvements, could you make to contribute to protecting the rights of a person with dementia?

Record your answers here:

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Activity

To explore this issue further read Bill's story.

Bill lives at home and receives informal support and care from a neighbour, out of goodwill and community spirit. The neighbour has observed that Bill has become upset at times when he receives letters from friends telling him of news, and these can include recent deaths. The neighbour decides that to protect Bill, they will censor his mail and remove handwritten letters from his mailbox before Bill can see them.

Imagine you support Bill in his home and discover this is happening.

What would you do?

Record your answer here:

In a situation like this you should speak to your manager. Later on in this module we will explore the Adult Support and Protection Act, 2007 in more detail. This Act provides a further legislative framework to support and protect people.

The Adults with Incapacity (Scotland) Act, 2000

The Adults with Incapacity (Scotland) Act, 2000, provides a legal framework for making decisions on behalf of a person who does not have the capacity to make decisions.

- It covers the person's welfare, property, financial affairs and medical treatment.
- It enables people to make their own arrangements for how their affairs should be managed if they lose the capacity to make decisions in the future.
- It recognises that, as far as possible, people should have autonomy and be able to control their own lives, and another person can only make decisions on their behalf when it is justified and necessary.

Remember

People should not be making decisions for someone else if that person has capacity to make decisions

What is capacity and incapacity?

Under the Adults with Incapacity (AWI) Act all adults are presumed to be legally capable of making personal decisions and of managing their own affairs unless it is established that they lack capacity to do so. This applies even when the decisions might seem unwise.

'Capacity' means the person's ability to use and understand information to make a decision. The person needs to be given appropriate information, provided in a way that they can understand, so they can make a decision based on this information.

Capacity in relation to **consent to treatment** means people are capable of understanding the nature, implications and consequences of their decisions.

A person is considered to have capacity to consent to treatment if they:

- Understand in simple language what the treatment is, its purpose and nature and why it is being proposed.
- Understand its principal benefits, risks and alternatives and be able to make a choice.
- Have a general understanding of what the consequences will be of not receiving the proposed treatment.
- Can retain the information long enough to use it to weigh up the possible outcomes in order to arrive at a decision.
- Can communicate that decision to others.
- Can hold this decision consistently. This includes occasions when a person has difficultly in remembering a decision but, given the same information at another time, they make a consistent decision. This makes their decision valid.

Capacity is **not** an all or nothing concept – a person may not have capacity at a particular point in time, or for a particular decision, but this does not mean that they will never have capacity to make any decisions.

The ability of a person with dementia to make a decision can vary enormously. Most people can make decisions about some aspects of their lives, but may need support in other areas. For some people the ability to make decisions can vary depending on their capacity at any point in time, and this can be influenced by many factors, including:

- Personal, physical, psychosocial and situational demands placed on the person, such as pain, discomfort or illness. It may be that they are in a noisy or unfamiliar place, or the room temperature is too hot or cold. Also the person may be more able to make decisions at different times of the day.
- The resources and supports the person has available to them to help them make decisions, such as communication aids.
- The impact on the person's capacity to make decisions if they are in pain or discomfort, or taking medication that causes drowsiness.
- Conditions that can affect decision making capacity can include infections such as pneumonia, urinary tract infection, influenza and delirium.
- The person may be experiencing mental health problems or become emotionally distressed by a situation. For example if the person's capacity to consent to admission to hospital is being assessed the person may be distressed because of past negative experiences, or a specific fear of hospitals.
- Relationships between people may impact on the person's ability to make an autonomous decision. For example if the person feels threatened, or put under undue pressure by another person.

People's capacity to make decisions may be diminished temporarily or permanently, partially or totally. For example, as a person progresses through the later stages of their dementia journey they may have difficulties understanding complex information. An example is someone considering having planned surgery, like a knee replacement or cataract surgery. They may not have capacity to decide whether the benefits outweigh the risks of the surgery. The person's capacity to process the information could be affected by being tired, anxious or not having time to process the information. It may be that after a period of time, when relaxed or with help from another person they are able to make an informed decision.

Module 5: Supporting and protecting people's rights

The key elements of the AWI Act which may be relevant to you in your practice to enable you to understand, support and protect people with dementia are as follows:

Power of Attorney

'Power of Attorney' is the name given to a person who has been granted the power to make decisions on behalf of the person who is incapable to make decisions on their own. A 'Power of Attorney' is taken out in the same way a person creates a will, by providing a statement in writing, usually with legal help. The document must include a certificate from a solicitor or medical practitioner who has interviewed the person immediately before the document was signed.

How the 'Power of Attorney' works is that a person gives permission to someone they trust to make decisions when they are no longer capable of making them. A solicitor or medical practitioner has to agree that the person has capacity, knows and understands what they are doing when they sign the statement.

The legal terms relating to power of attorney are:

- the person giving permission to someone else is known as the **granter**;
- the person, who is given the powers, is called the **attorney**, or may be also known as the **proxy**.

There are 2 types of 'Power of Attorney' - **Continuing** and **Welfare** attorneys.

Continuing Attorney

Continuing powers of attorney mean others can only manage the **finances and property** of another person and their powers can start immediately after the agreement is signed. The person giving permission (the granter) may not want this to happen and can specify that the powers should start only when they have lost capacity to manage their own financial affairs. When continuing attorney is in place, the 'Power of Attorney', when necessary, would have access to the person's finances and could arrange to do things like pay household bills and collect pension payments.

Welfare Attorney

Welfare Attorneys have power over the person's **personal welfare**. These are things that affect the person's physical and emotional well-being, for example, physical and mental health and protection from abuse and harm (other than financial harm). It can include choice of medical care and treatment, diet, hygiene, clothing, meaningful social contact, and where the person lives.

Welfare Attorneys can only start making decisions on behalf of the person, once the person has been assessed, and it is agreed they no longer have capacity.

It may seem that the 'Welfare Attorney' could potentially have total control over the welfare decisions of another person. In reality, this is where the principles of the AWI Act guide us, and any action should always be the least restrictive option chosen for the person with incapacity.

Under the principles of the AWI Act the 'Welfare Attorney' also has the duty to encourage the maximum use of the person's skills. For example, a person with dementia may require treatment to have a cyst removed which medical staff suggest they have under general anesthetic, despite the usual treatment being delivered under local anesthetic. Their Welfare Attorney could give consent but may suggest that the person retains enough understanding to have the treatment under local anesthetic, therefore, upholding their right to least restrictive option and maximum use of their skills.

The Welfare Attorney cannot give consent for medical treatment for a mental disorder. An example is if a person with dementia is in hospital being treated for depression and the Psychiatrist wants them to take anti depressant medication, but the person refuses this. In this instance the Welfare Attorney cannot give permission and this would require application of the Mental Health Act to ensure even more stringent safeguards are in place to give medication against a person wishes.

Remember

the Welfare Attorney cannot give consent for medical treatment for a mental disorder against the person’s wishes.

While both of these examples are health care related it is not unusual for similar situations to occur in social services. An example of this is a Welfare Attorney agreeing with social services that the person with dementia would benefit from moving from their own home to a care home. The Welfare Attorney could give consent to the move but suggest that the person has enough understanding to make a decision about their choice of care home. This would support the person to exercise their residual capacity and take account of their wishes.

All ‘Continuing’ and ‘Welfare’ Powers of Attorney must be registered with the Public Guardian. In return, the Public Guardian issues the attorney with a Certificate of Registration. The role and function of the Public Guardian are described later in this module.

Reflection

We are all encouraged to make a will and have advance statements, or plans, in place for what we would want to happen if we are unable to make decisions.

- How would you feel if it was suggested to you to appoint a ‘Continuing’ and ‘Welfare’ Power of Attorney?
- Would it be easy to decide who to appoint and what would influence your decision?

Record your answers here:

Activity

Think about someone with dementia, their family and carers that you work with who may be unaware of the AWI Act.

Based on what you have learned so far what information would you give them?

Record your answer here:

Intervention and Guardianship Orders

Intervention and Guardianship Orders provide legal authority for someone to make decisions and act on behalf of a person to safeguard and promote their interests. They can only be applied for when no relevant Power of Attorney is in place and the person has been assessed as lacking capacity to make decisions. Both orders can cover property and financial matters, or personal welfare including health, or a combination of these. The main difference between them is that an Intervention Order gives permission for a one off action or to make a single decision, for example selling a home or deciding what medical treatment is best for that person at a particular time. Whereas a Guardianship Order can be applied for when there are several issues to be dealt with, and decisions will need to be made to manage someone's affairs on an ongoing basis.

Remember

If you are working directly with a person who is unhappy about decisions being made for them, you may be the only person who is aware of their unhappiness and you have a duty to act in the interests of the person you care for.

We will explore this a bit more with Ellen's story.

Ellen's Story

You are working with Ellen and supporting her at home following her brief admission to hospital. Caroline, Ellen's daughter, visits regularly and has informed you that prior to going into hospital Ellen appointed her as Continuing Power of Attorney and Welfare Attorney.

Six months have passed and you have got to know Ellen very well and she continues to have capacity for most decisions. You notice that every time Caroline visits they argue about money and Ellen gets very upset and distressed. Caroline reassures her that she is only paying her bills and using money to buy new clothes for Ellen. After Caroline leaves Ellen is still distressed and states "I will soon have nothing left".

What action should you take?

While Caroline says she has Power of Attorney we do not know this is the case, and even if she does, the use of finances should be in Ellen's best interest. It may be that Ellen cannot recall that she agreed to this when she had capacity to do so.

Regardless of what we speculate, there may be a potential issue of financial abuse of Ellen.

You are required to report it to your manager who must contact the Local Authority and the Public Guardian. If you do not have a manager you can contact these agencies yourself. They have been set up in this way to allow you to contact them directly. They can then carry out a monitoring visit to Caroline and take any necessary steps. It is also important that Caroline continues to involve Ellen in her finances as much as possible and doing so may be enough to allay any concerns.

The AWI Act created roles and functions for a number of organisations and bodies to ensure people who are considered under the Act are protected. These are:

The Public Guardian

The Office of the Public Guardian has duties to register Powers of Attorney, Intervention and Guardianship orders, and to give permission for the withdrawal of funds from the person's bank account. It also receives and investigates complaints and has a duty to give advice and information on request. Anyone can contact the Public Guardian for information, or to raise a concern.

The Mental Welfare Commission for Scotland

The Mental Welfare Commission for Scotland is required to protect people who are assessed as incapable due to mental disorder. The term mental disorder is used because of its legal description in the Mental Health Act. The Mental Welfare Commission also has a duty to enquire into any potential ill-treatment, deficiency in care or treatment, improper detention or possible loss or damage to the property of a person with mental disorders.

The Local Authority

The Local Authority has a variety of duties, including a supervisory role in relation to the provisions of the Act. They will also often make applications for Intervention and Guardianship Orders and investigate complaints.

Activity

Think of someone who you know as a friend or family member that you care about who has made a decision that you think is not in their best interests (this could be a financial or personal decision).

Why do you think they made that decision?

Did you tell them how you felt about their decision? If not, why not?

If you did, how did they react?

Record your answers here:

Reflection

- Now think of a decision that you have made for yourself that you do not think was in your best interest. Why did you make this decision?
- Now think of a decision that you have made that has been criticised by someone whose judgement you respect? How did that make you feel about the decision you made?

Record your answers here:

It is likely that thinking about those questions aroused some strong feelings. The right to make decisions for ourselves is something we value and take for granted. We generally believe that no-one has the right to question our decisions unless we ask them to, even if we are aware that decisions we have made may not always be seen as wise.

We can also find it very difficult when people we know make choices that we think are not in their best interests, and want to intervene. This is especially true when that person has a condition that we think may be affecting their ability to make good decisions.

People often think that there should be an easy way for families and the state to take over decision making in these situations. The reason there is not, is because of the right we all have to make our own decision with no interference from others. We need to remember that people with dementia, their families and carers are entitled to these same rights.

Assessment of capacity

The AWI Act gives medical practitioners the main responsibility in deciding whether a person is incapable of making particular decisions or taking specific actions. Nurses, dentists and ophthalmic opticians can also assess capacity and authorise treatment but only within their own speciality, for example a nurse can only authorise nursing interventions. The assessment of whether the person is incapable of certain decisions or actions is central to most parts of the Act.

A number of factors should be considered in making this assessment, these include whether the person has the following:

- Information appropriate to the person's ability to understand.
- Ability to consider choices, reason, and reach a decision.

- Ability to receive information and express views sufficiently to communicate a decision.
- Freedom from pressure from others.
- Ability to be consistent in decision making.

The medical practitioner makes the final assessment of capacity but he/she will be expected to use multi-disciplinary and agency information and reports as part of the overall assessment. Under the principles of the AWI Act, the doctor must also consider the person’s past and present wishes and feelings and, where reasonable and practicable, seek the views of significant others.

People with dementia can retain capacity to make decisions until the very later stages in their journey. However, their ability may fluctuate from day to day and hour to hour and this needs to be considered during assessment. It is often the staff who work directly, and on a regular basis, with the person who will notice these fluctuations and have a central role in contributing to assessment of capacity.

Likewise people should be supported and encouraged to exercise what is referred to in the AWI Act as **residual capacity**. This means that although they may not have capacity to make major decisions, they should be enabled to make decisions where ever possible. For example, the person who is assessed as lacking capacity to manage their finances or understand the implications of medical treatments may still be able to make choices about food, clothing and activities they want to engage in. Every effort needs to be made to ensure this happens.

Activity

How could you ensure that you support the person with dementia that you work with to have as much choice as possible in their day to day life?

Record your answer here:

Consent to medical treatment

It will be normal practice for you to seek consent from the person you are working with before undertaking any intervention or treatment. In many instances this may be implied consent. For example, if you are supporting a person to wash and ask if they would like to have a bath the person may not respond verbally but accompany you to the bathroom; and their action implies that they consent. Similarly if a healthcare professional asks a person if they can take a blood sample and the person puts their arm out this implies their consent. However, if the person refuses or resists, their decision must be respected and you cannot continue with the intervention or procedure without an assessment of capacity under the AWI Act.

The AWI Act defines medical treatment as 'any healthcare procedure designed to promote or safeguard the physical or mental health of the person'. This could include the provision of: nutritional care and fluids; skin care; continence care; pain relief; help with mobility; communication aids; eyesight and hearing support; dental care and oral hygiene, as well as medication.

If a person is assessed as not having capacity to consent to the treatment, the responsible medical practitioner, or other health professional will complete and sign a **Section 47 Certificate of Incapacity** and a **Treatment Plan** detailing all the care and treatment covered by the certificate. This will allow the person to receive the daily treatment/ interventions without having to get consent for each one when it is needed.

Remember

It is illegal for a family member or other relative to consent to treatment if they are not a proxy with permission to do so.

Medication issues

We will continue to explore consent to treatment in relation to the administration of medication. Consider Jim's story below.

Jim's Story

Jim, who we met earlier, lives in a care home but this situation could happen in an acute hospital, community hospital or his own home.

Jim is on medication for angina and although he can become resistive and upset when being given his medication, his wife Jane has said staff can give it to him crushed up in his food. You are working in the home one afternoon and when you offer Jim his medication he pushes your hand away. A senior member of staff asks you to give Jim some bread and jam with his medication crushed up inside.

What things to you need to think about in this situation?

Record your answers here:

Covert medication is the administration of any medical treatment in disguised form. This can involve disguising medication by administering it in food and drink. Sometimes it may involve medicines being administered in an altered form e.g. tablets crushed or capsules opened. However, other medicines can be given covertly without being altered or mixed with food or drink e.g. patches or liquid medicines. The essence of covert administration is that the person is unknowingly taking medication.

Remember

You need to be aware that altering medication in this way can mean it will not have the desired effect or it could result in serious health consequences for the person.

- You should **never give medication covertly** even if the person's family or carers request or insist it without ensuring proper assessment has taken place and safeguards are in place. **Otherwise it is regarded as an assault on the person**
- If medication is given covertly this is only when it has been agreed with a pharmacist and the health and social care team working with the person.
- It must be detailed and recorded in the prescription as a means of administration.

While there may be occasions where there is no alternative, and it is medically and ethically justified to give covert medication, it must never be given to someone who is capable of deciding about medical treatment.

Every effort to gain consent must be recorded, and details of multidisciplinary discussion and the Pharmacist recommended approach must be recorded in the person's care plan and the prescription which must be signed on each occasion.

More guidance about covert medication is available on the Mental Welfare Commission for Scotland's website.

The Mental Health (Care and Treatment) (Scotland) Act, 2003

The Mental Health (Care and Treatment) Act describes what is required when working with people who are being treated for 'mental disorder' under this Act. It includes people who have mental health issues, learning disabilities or a personality disorder. It may apply to someone with dementia if they have mental health issues and require treatment. The Mental Health (Care and Treatment Act) sets out:

- When and how a person can be treated if they have a 'mental disorder'.
- When a person can be treated or taken into hospital against their will.
- The person's rights and the safeguards which ensure that these rights are protected.

Your role may require that you know details of the provisions of the Act and you may wish to access the NES **Mental Health (Care and Treatment) (Scotland) Act 2003 Learning Resource**.

However it is essential that you are aware of some of its safeguards such as 'Advance Statements', 'Personal Statement' and 'Independent Advocacy' as they can help to support a person with dementia to have their rights protected.

Advance Statements have a specific legal meaning in the Mental Health (Care and Treatment) Act. They set out the way a person wishes to be treated, or not treated, in the event of becoming mentally unwell and unable to make decisions about their treatment. They are intended to improve the person's participation, in line with the principles of the Act and require tribunals and others providing treatment to take account of the past and present wishes and feelings of the person. An Advance Statement can be made by anyone, even if they are under 16, as long as they understand what they are putting in the statement and the effect it may have on their care and treatment in the future. In order for an Advance Statement to be valid it must be in writing, signed and witnessed by an 'appropriate' person as outlined in the Act.

Personal statements can be attached to an Advance Statement but do not have the same status in law. They set out what the person would like to happen if they, for example, have to go into hospital, including issues like: what to tell their employer; care arrangements for pets; and other domestic matters can be included. It is helpful if a personal statement is signed and dated but there is no requirement for a personal statement to be witnessed. In addition (as discussed in Module 2) a person with dementia can make an **Advance Plan** detailing wider care and treatment options that would be considered at a later date if they do not have capacity to make decisions.

Independent Advocacy supports a person's right to have their voice heard in decisions made about their health and well-being if, for whatever reason, they find it difficult to put their own case to service providers, or do not feel in a strong position to exercise or defend their rights. Independent Advocacy is particularly helpful for people who are at risk of being mistreated or ignored, or who wish to negotiate a change in their care, or are facing a period of crisis. The Act makes it a right for people who have a mental disorder to have access to Independent Advocacy and places a duty on NHS Boards to ensure it is provided.

The Adult Support and Protection (Scotland) Act, 2007

The Adult Support and Protection (Scotland) Act, 2007 aims to protect adults who are unable to protect themselves and are at risk of harm. There are many circumstances that can place a person at possible risk of harm, such as mental health difficulties, dementia, learning disabilities and acquired brain injury. It is important to recognise that having a particular condition such as dementia does not automatically mean an adult is an 'adult at risk'. To be an 'adult at risk' the person must meet the 'three point test'. If an adult meets only one or two elements of the three point test, they cannot be considered an adult at risk.

Three point test

1. Unable to safeguard their own well-being, property, rights or other interests.
2. At risk of harm.
3. Are more vulnerable to being harmed because they are affected by disability, mental or physical ill health.

An example of not meeting the three point test is, a young man who lives a chaotic lifestyle and drinks heavily. When drunk he invites strangers he meets in the pub back to his home. Frequently these people threaten him and take money from him leaving him with no money for food and household bills. He meets points 1 and 2 but not 3.

If however this man also had a learning disability, dementia or physical disability he would meet the three point test.

Harm and abuse

A person with dementia is similar to many other groups in society who may be at risk of harm from other people. This may be from people close to them, or working with them. Forms of abuse include:

- **Physical abuse –** being hit or injured on purpose.
- **Financial or material abuse –** such as theft, or misuse of money, property or personal possessions.
- **Emotional abuse –** for example, intimidation, threats, humiliation, and verbal or psychological abuse.
- **Sexual abuse –** the involvement in sexual activity that is unwanted or not understood.
- **Neglect –** from not providing the basics such as food, clothing, attention or care, and includes the failure to provide appropriate access to health and social care.
- **Discrimination –** treating people negatively because they are older, more frail or confused.
- **The misuse of medication –** giving medication inappropriately, overdosing or withholding medication.

Signs and symptoms of abuse may include:

- Injuries, bruises or weight loss.
- Behaviour changes - such as being withdrawn or depressed.
- Self harm.
- A dishevelled or unkempt appearance.

It is important to emphasise that **if you suspect someone is being harmed or you observe them being harmed, you have a duty to report it to your line manager**. Under the legislation, your manager then has a duty to report it to an Adult Protection Lead Officer who has access to an Adult Protection Committee. These have been established in all Local Authority areas across Scotland and are multidisciplinary committees with representation from various public bodies.

Remember

Never dismiss your information as being unimportant or trivial, you do not have to be certain a person is being harmed to report it, only to suspect. Your information may be the crucial part of the full picture.

Margaret's Story

Margaret has now returned home following an admission to a community hospital and you are one of 4 staff supporting her. You notice that she has become very quiet in the past couple of weeks and jumpy at the slightest noise. You continue to encourage her to engage in conversation and mention another team member's name who will be visiting the next day. Margaret does not respond but you notice that she looks upset and worried. When you ask her what the matter is she does not respond and shakes her head.

What would you do?

You tell your manager what has happened and that you suspect this member of staff has a negative attitude to supporting

Margaret because of the way she speaks about Margaret to you.

Your manager agrees to visit Margaret and later lets you know that she does not think there is any problem. You notice that over the next couple of weeks Margaret continues to be increasingly withdrawn and upset.

You have already reported your concerns so what can you do now?

You have the option to go back to your manager. Additionally, you may report it directly to the Local Authority Lead Officer if you believe your concerns are not being responded to. It is very important that you do not engage in further investigation yourself as this may well become a police matter and you could be seen to be tampering with evidence.

It does not matter if it transpires that there is no case of abuse - you will have taken the appropriate action to protect Margaret.

You should ensure you know how to contact your Local Authority Lead Officer. You can find this information by contacting your Local Authority Social Work Department.

Working with risk and risk enablement

Life is never risk free, it is part of all our lives, but assumptions about the capacity of people with dementia to make decisions and take risks can result in their quality of life being restricted. We need to balance risk and autonomy with our duty of care when we are working with the person with dementia.

In this section of the module we will explore these issues in more detail with reference to Iain’s story.

Iain’s Story

You will remember from Module 4 that Iain lives in a care home. He spends long periods of the day standing at the exit door of the home, and when anyone comes in and out of the door he tries to leave, and is prevented from doing so.

At other times Iain is restless and constantly walks around the home and goes into other residents’ bedrooms. He is regularly escorted out of the rooms by staff.

Staff are finding this a difficult situation to manage - **but imagine how it must feel for Iain!**

Throughout this learning resource we have stressed the importance of really knowing the person, their life story and history, and working with their strengths and assets - so here is a bit more information about Iain.

- Iain worked as a Joiner.
- He is married to Mary.
- He has 2 children and 6 grandchildren.
- He is a keen bowler and enjoys gardening, and used to have an allotment.
- He is very physically fit and led an active life.
- He had pet dogs all his life, and used to walk them at least 3 times a day.

Activity

Drawing on the learning you have undertaken so far, and the information you read about Iain previously:

How could you draw on Iain's strengths to support him in what must be a difficult situation for him?

Can you think of any meaningful activities that Iain could be involved with in the care home?

Can you think of any meaningful activities Iain could be engaged in outside the care home?

Record your answers here:

Walking about in what appears to be an aimless manner, often referred to as 'wandering', is seen in many care settings as 'problem' behaviour to be stopped. It frequently results in the person with dementia being restrained.

The term 'wandering' has very negative connotations and is demeaning to the person. While on occasion the person may appear to be walking aimlessly, it usually will have meaning for the person and we need to understand where the person is going, and provide them with a safe means of moving around freely.

Remember

People with dementia need to feel safe and secure and are able to be as independent as possible.

Risk and restraint

At times actions may be taken by staff, or families and carers, with the intention of minimising risk, but in effect amount to either 'direct' or 'indirect' restraint. The Mental Welfare Commission for Scotland describes restraint as:

- The planned or unplanned, deliberate or unintentional actions of staff to prevent a person from doing what he or she wishes to do.
- Placing limits on the person's freedom of movement.
- Defined in relation to the degree of control, consent and intended purpose of the intervention.

Being restrained can be frightening, potentially dangerous and undignified. Restraint may be regarded as a **criminal offence** committed by an individual worker rather than their employer, unless carried out within the legal processes described earlier in this module. It may take the form of direct physical/mechanical restraint; modification of design; medication; or psychological restraint. All these methods prevent, or restrict, the person's movements within their own home, a care home or hospital.

Physical and mechanical restraint may include:

- laying a hand on the person to stop them moving;
- use of a restraining chair;
- trays fixed to chairs;
- bed sides;
- restricting the person's movement while they are in bed, for example, by tightly tucking in bed clothes.

Modification of design includes: locked doors; doors with code number pads; electronic tagging devices; and video surveillance.

Restraint also includes the use of covert medication (previously discussed in this module).

Remember

The use of sedative or tranquillising drugs purely to prevent someone moving can never be justified.

Psychological restraint refers to a number of things, including what could be seen as bullying attitudes, like shouting at, or excluding the person, and leaving the person afraid to ask for help. For example, telling the person they are not allowed to get out of bed in an unfriendly or brusque manner or placing their walking aid out of reach.

It is also important to be aware of the impact of restraint on the person. As well as being traumatic it may lead to feelings of shame, loss of dignity and self respect as well as social isolation. It is also likely to cause the person to become anxious and distressed.

Restraint should only be used if the Adults with Incapacity Act is applied and in accordance with the principles of the Act and supporting guidance, and be subject to ongoing monitoring and review.

Risk and risk enablement

People with dementia often feel that 'dementia' becomes the only thing others know about them. But they remain individuals in their own right and dementia is not the most important thing about them. Many people are still able to do what they did before, despite their life changing and some things becoming increasingly difficult to do.

In terms of best practice the recommended approach to working with risk and people with dementia is 'risk enablement'. This takes a tailored approach to risk by acknowledging that dementia affects different people in different ways.

Traditionally approaches to risk management with people with dementia focus on the **downside of risk**, for example the risk that an event will turn out worse than expected.

If we consider Iain's story we can see this:

- Staff feel Iain is at risk if he leaves the care home because: he may fall; he might get lost and not be able to find his way back; he might not be able to cross the road safely and get run down by a car.
- His wife Mary may also be very anxious about him leaving the care home, as prior to his admission he left their home several times and got lost and had to be brought home by the police.

However a 'downside' approach to risk can be very negative in focus with little room for optimism, or the potential for working alongside risks, or supporting people to take risks.

Another approach is to think about the **upside of risk** and this is essentially what risk enablement is about. Again thinking about Iain - what if he is enabled to leave the care home? Are there positive chances that this will improve: his quality of life; enhance his well-being and maintain his physical and mental health?

This alternative 'upside' approach to risk focuses on Iain's strengths and assets.

Remember

Ideas about risk are personal and are built up over a lifetime and it should be the person with dementia that is at the heart of decisions.

Negotiating risk is neither the elimination of any activity that might produce a downside, nor an acceptance of all activities without boundaries. It is a conversation about who the person is, and asks:

- how they stand to benefit from engaging in an activity.
- what the downside risks are.
- can they be mitigated to an acceptable degree of support?

Frameworks for risk enablement decision making

The development of risk enablement plans can enable staff to support the person in taking risks. This will involve detailed discussion with the person with dementia, their family and carers as well as other professionals and care providers working with them. Risk enablement needs to be taken forward using a 'team approach' and will involve a range of professionals working at the 'Enhanced' and 'Expertise' levels of **Promoting Excellence**. At Skilled level your key contribution to this will be to:

- Support people with dementia in risk enablement by contributing to risk assessment and management.
- Provide information and access to supports for risk enablement and maintaining independence, such as tele-healthcare. This is covered later in this module.

The following framework for decision making can also help in this process:

- Have you got all the information you need?
- What are the risks associated with each available choice?
- What risk is being taken (and by whom?)
- What are the positive outcomes of taking the risk?
- What strengths can be identified?
- What steps need to be taken to manage risk taking?
- What could go wrong and how could that best be managed?
- Accept that some things can go wrong: who can help manage the fear or guilt?

Returning to Iain's story we can apply this framework.

Iain's Story – returned

Iain was having a distressing time in the care home. He was constantly standing at the exit door and trying to get out. At other times he was very restless and walked constantly, often going into other people's rooms. Iain was constantly subject to a form of restraint from the staff who were worried about the risk to him if he left the home.

However, staff recognised this was an unsatisfactory situation for Iain and had also learned more about his strengths and assets by reviewing his Life History, speaking with his family, and noting wishes for the future Iain had identified in his Advance Plan. Iain had been very clear in his Advance Plan that the things that were important for him in the future were being able to enjoy his previous interests, and most importantly be able to get outside to enjoy his previous activities.

Following discussion with Iain and his wife Mary the following actions were agreed:

- Iain would be enabled to access the care home garden independently.
- A volunteer (Jim, and his dog Amber) would visit Iain on a twice weekly basis and they would go for a short walk outside.
- As an experiment Iain would be enabled to leave the care home on the occasions when he was standing at the exit door. A staff member would discreetly follow him and assess risk.

What happened next:

In terms of Iain's story the initial risk enablement plan went well, and everyone involved, including his wife Mary were in agreement that the benefits of the plan for Iain's well-being completely outweighed the risks to Iain's safety.

- Iain enjoyed spending time in the care home garden. Staff left a gardening trowel and fork around, which Iain sometimes used to work the soil in the borders. On a couple of occasions he had stumbled, but not fallen.
- Iain seemed to greatly enjoy his short walks with Jim and Amber the dog.
- The observation from the experiments of Iain leaving the care home for a walk were that Iain just tended to walk up and down the road a few times and then return.

Reflection

Consider the types of restraint described earlier in this module in relation to your role and the setting you work in:

- Are any people being subjected to physical or mechanical restraint?
- What are the reasons for this, for example: duty of care; or to manage risk to the person or others?
- Considering the protective legislation we have discussed already in this module - how is this being applied to safeguard the person who may be being physically or mechanically restrained?
- How do you feel about this given what you have learned so far about risk enablement?
- What changes could be made in the area you are working in and to your practice?

Record your answers here:

Risk enablement and assistive technologies

Many of the assistive technologies/tele-healthcare approaches described in Module 2 are being used in the people's own home, care homes and hospitals to enable people to take risks and improve their quality of life. This recognises the positive benefits of the person being able to move around in promoting their health and well-being, as well as reducing risks.

There are many types of Global Positioning Systems (GPS) and tracking devices available, including: watch-based devices; smart phone applications; and key rings and pendants. They enable a person with dementia, who may be at risk of getting lost, or going missing, to have greater freedom, maximise their independence and improve their quality of life.

However they do impact on the person's privacy and may restrict their independence.

Iain's Story – returned

In Iain's example, the observation from the experiments of Iain leaving the care home, with discreet staff support, were that Iain just tended to walk up and down the road a few times and then return. However on 2 occasions he walked a bit further and was not able to find his way back.

The team supporting Iain, and Iain's family agreed that he should continue to be enabled to leave the care home independently, but any risks should be managed by him wearing a Global Positioning System (GPS) tracking device.

This would mean that in the event that Iain did not return to the care home the staff, and his family, would be able to detect his whereabouts via the device to make sure he was safe.

Iain's Advance Plan had stated he would like such assistive technical supports to be used, if they enabled to him to enjoy and engage in his valued activities.

While use of such approaches may have been helpful to Iain, it is important to note that when considering these technologies, we need to be aware of ethical issues, including:

- if the person would have wanted them to be used;
- any potential for these practices to become a restraint, as well as stigmatising for the person;
- any impacts on the person's privacy or reduction in their choice of activity;
- any adverse effects for the person - for example, if the person has to be constantly brought back to a care setting this may lead to increased stress and humiliation for them.
- that devices are only used for the right reason - primarily for the benefit of the person, although they are likely to also benefit the family or carer. But the person's needs must always come first;
- they are never used without the person's knowledge and consent – or if the person is not able to consent, appropriate legislation is applied.

Before ever considering the use of these technologies, changes in the physical and social environment of the care setting need to be taken into account, including ensuring the person being engaged in person-centred occupation and stimulation.

Remember

Technology should not be used as a substitute for appropriate levels of personal support, care and human interactions in care settings, including the person's own home.

In this module we have previously explored the issue of capacity. Remember that people's capacity may fluctuate, and will likely diminish as the person progresses to the later stages of their dementia journey. It is at this point that staff working with the person may feel under considerable pressure to eliminate risk. Careful assessment of risk and risk enablement remains important.

These considerations also apply to all tele-healthcare devices or systems to monitor people, or that allow someone else to track them, such as GPS devices and other technology. It is essential that the person with dementia, and their family and carers, are made aware of the potential benefits and limitations of these technologies as part of their post diagnostic support and to support their development of Advance Plans. This will enable the person to make an informed choice about the range of technologies they would consider and support decision making when the person is no longer able to give consent.

As with all tele-healthcare, if the person is not able to give informed consent to the use of monitoring and tracking devices they should only be considered through the application of the Adults with Incapacity Act, and in accordance with the principles of the Act.

The Equality Act, 2010

The Equality Act, 2010 updates other laws relating to discrimination and bans unfair treatment as well as helping to achieve equal opportunities in the workplace and in wider society for everyone. It applies to all service providers and those providing goods and facilities in the United Kingdom.

The Act protects people from direct discrimination, discrimination arising from disability, harassment and indirect discrimination. The Act identifies 9 characteristics which cannot be used as a reason to treat people unfairly.

These are:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation

In Module 1 we explored some specific equality and diversity issues in relation to people with dementia.

Module 5: Supporting and protecting people's rights

Module summary

In this module we have explored the rights of people with dementia and how we can use the range of protective legislation in Scotland to support them in exercising their rights and choices. We examined the concepts of capacity, risk, risk enablement, harm and restraint and considered their relevance to your practice.

We hope it will give you greater confidence in recognising and challenging when a person with dementia is being denied their rights.

Reflective Account

Write a reflective account taking into consideration your learning from Module 5.

Below is a suggested structure that you may find helpful in writing your reflective account.

Please ensure that you anonymise any information

What happened?

Identify and describe a situation or incident where you were supporting a person with dementia and you had concerns about their well-being. When recalling this situation you may wish to consider the following:

- Adult Protection issues in relation to dementia.
- The principles of Adult Protection legislation.
- The range of legislation and policy that protects the rights of people with dementia in Scotland, for example capacity and consent and risk and risk enablement.

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

- How did you feel about the outcome of the support that you provided at the time?
- What do you feel about that now in light of your learning, having completed the module?
- What did you do that went well?
- Do you think your actions helped to improve quality of life for the person you were working with?
- What might you now do differently?

Now what will you do in the future?

- How will this affect the way you work with people with dementia in the future?
- Would you act differently or would you be likely to do the same?
- What further learning do you need to undertake to enhance your understanding of Adult Protection in relation to people with dementia that will help you support people to improve their quality of life? You may want to record this using the **Action into practice** activity at the end of this module.

Action into practice

From your learning in this module

- How does your work setting actively promote the rights of people with dementia?
- Find your organisation’s policy on risk enablement and restraint.
- Check that it is consistent with your learning in this module and list 2 changes you will make in practice to ensure your policies are implemented in a person-centred and rights focussed way.

Make notes of your responses below: