# Enable rights and choices of indivduals with dementia whilst

Health & Medicine, Disease



1 UNDERSTAND KEY LEGISLATION AND AGREED WAYS OF WORKING THAT
SUPPORT THE FULFILMENT OF RIGHTS AND CHOICES OF INDIVIDUALS
WITHDEMENTIAWHILE MINIMISING RISK OF HARM

1. 1The key legislations are Adult and Incapacity Act 2000, MentalHealthAct 2007, DisabilityDiscriminationAct 1995, Safeguarding Vulnerable Groups Act 2006 and the Mental Capacity Act 2005. Human RightsAct. These are all core principals of legislation regarding an individual with dementia.

Policies and procedures and agreed ways of working and safeguarding Individuals is another key factor. All organisations and authorities have aduty of caretowards an Individual with dementia, GPs, Social Workers, Health Visitors, Familyand Carers. All Individuals with dementia have the rights to make choices. Individuals with dementia should be encouraged to make as many decisions as possible for them; however they must be guided so they stay within the Mental Capacity Act 2005.

Related article: Legal and Organisational Requirements for Dealing With Complaints

We must assume that the Individual with dementia has capacity unless it has been assumed that they lack the capacity to make choices. We must not think that an Individual is not to be treated as unable to make a decision unless this has been established. An Individual is not to be treated as unable to make a decision because they might not always make a wise decision. If a decision is made under the Mental Capacity Act on behalf of the Individual, the decision must be made for the best interests of the Individual.

Before a decision can be made on behalf of the Individual we must ask ourselves whether the purpose of the decision can be effectively achieved in a way that would not restrict the Individuals rights and freedom of choice and action. We also have to adhere to the Human Rights Act and code of Practises. The Individual with dementia will have to be risk assessed. The Individual will be encouraged to make their own choices and decisions, if they make an unwise decision they should be offered other options which will help lead them to make a wise decision.

Risk needs to be balanced with Independence and Individuals choices and working within legislations. We should not assume that all Individuals with dementia are vulnerable; this depends entirely on the stages of dementia. We should not restrict the Individuals from having choices and making decisions for themselves. Risk assessments can be very complex as no two assessors will come to the same conclusion regarding the Individual. We have to let the Individual with dementia take a certain amount of risk for themselves, allowing this to happen makes the Individual feel worthy and independent and more at ease with their illness.

If we were to put everything an Individual did down as a risk the Individual would feel worthless, inadequate, and useless and they would feel that they are a burden on their family. We have to weigh up the risk against the danger this is the key. If we were to take away all the choices and decisions and have someone else make these decisions and choices on behalf of the Individual this would have a negative impact on the Individual as they would be having everything took away from them and they wouldn't feel in control.

A positive impact on allowing the Individual to take risks, the Individual can still do their day to day activities etc, make their own meals, make cups of tea, do their own housework, laundry, take bathes, go for walks. Wherever possible we should eliminate high risks and look at ways to reduce these risks so they become low risks etc, supporting an Individual to make their meal observing them so they don't hurt themselves, or accompany them on a walk etc.

1. 2People with dementia may have other difficulties too, like loss of hearing, make sure that the hearing aids are working well and that you speak to them in a loud clear voice so they can understand you. The person could also be in pain or discomfort, they could be having side effects from medication which will affect the way they communicate with you. Other problems would be eyesight, make sure they are wearing the correct prescription of glasses.

Dentures are important as well, if the dentures are loose fitting then this will affect the person's speech and this will be frustrating for them . 3Personal Information comes under the Data Protection Act 1998. We have to make sure personal Information is confidential. We have to know how to handle the personal Information, agreed ways of working, policies and procedures are all legislation frameworks. The Information should be processed fairly and lawfully. The Personal Data should be processed for limited purposes. The information should be adequate, relevant and the information should be for the purpose of whom the information is processed for.

The information should be kept up to date and accurate. The information should not be kept longer than intended for. The Persona Data will be processed in accordance with the rights of data subject under the Act. Measures are in place to avoid the information being lost or unauthorised and unlawfully processed or damaged to. The Personal Information shall not be transferred to another country outside the European Economic Area unless that country ensures an adequate level of protection for the rights and freedoms of data.

Personal Information may be shared with others, consent is needed to do this at all times from the Individual or in the case of an emergency, abuse, or if neglect is suspected. If the Individual is mentally incapable, informed consent should be given by the family or next of kin. Information that is shared with an advocate should be information that is for the Individuals best interest, Exchange of information from one organisation to another should be shared and done securely and access to the information should be controlled.

Personal Information may be shared with carers who have access to the information regarding the service user. The carer will write up her findings when she has visited the service user and they will be on the log sheets in the care plan. When another carer goes to visit the service user they will look at the previous notes the other carer had documented and they will have a better understanding of the service user's situation and needs. This is one form of information sharing also the carer will access information from the care plan and from the med sheets.

If a service user was to be hospitalised the paramedics may need the care plan and log sheets so they can read up and see if any information documented is relevant to the response of the paramedic. Also if a service user was to go into a care home the care plan and log sheets would be taken in to the home so the relevant members of staff could read the data and have a better understanding of the service user. The Medication sheet would also be in with the care plan; a key factor is getting consent to access information.

BE ABLE TO MAXIMISE THE RIGHTS AND CHOICES OF INDIVIDUALS WITH DEMENTIA

#### 2. 1 SEE STANDARDS

2. 2It is very important not to assume that an Individual with dementia cannot make their own decisions. From the time the Individual has been diagnosed the time scale is important as this gives the Individual time and may be capacity or limited capacity to make own choices and decisions. This is the time when the relevant authorities should prompt the Individual and gather as much information about the Individual; this information can come from the Individual, the family, the next of kin.

Information on preferences, choices and decisions and wishes. Information on Individuals life experiences, strengths and abilities, family history, favourite foods, pastimes, hobbies, favourite drinks, dislikes, likes, favourite radio station, favourite tv programmes, routines, clothes the Individual likes to wear and socialising. All the information and choices and preferences will

help the Individual and the people supporting the individual prepare for the future. Early diagnosis of an Individual will give the Individual the rights to their freedom and this must be respected.

As dementia advances the risk assessment plan will need to be reviewed and the care plan may need to change to accommodate the changes within the Individual. We should still encourage the Individual to make decisions and choices as much as possible, bearing in mind the risks which come with these decisions and choices. All the choices and decisions should be monitored and recorded. Taking away the rights of an Individual with dementia can be soul destroying, it can be frustrating, the Individual may become depressed, withdrawn, feel isolated, worthless, a burden, emotionally detatched and angry.

Every emotion a normal person feels, the Individual with dementia will feel the same but on a higher scale. Dementia Individuals need to be in anenvironmentof comfort and empowerment. The Individual will respond better to a person centered approach. The Individual needs to feel a sense of belonging and attached, they need to feel included and feel part of a group or physical setting, they need to be occupied and kept busy just as they was in their everyday life before they got the illness. Their environment needs to be created so that the Individual has support and can do the things they have always enjoyed doing.

All Individuals with dementia have their own personal Identity they are all unique so learning about their life stories and experiences can be of benefit

to the care they receive as the information learnt can be built into their interactions within their care plan needs.

### 2. 3 SEE STANDARDS.

3 BE ABLE TO INVOLVE CARERS AND OTHERS IN SUPPORTING INDIVIDUALS WITH DEMENTIA

### 3. 1 SEE STANDARDS.

3. 2There can be conflicts and disagreements between carers and Individuals with dementia and also conflicts with family members. When the problem arises we have to address the problem and try and resolve the problem as soon as possible.

We have to take into account the rights and choices of the Individual and balance this with the risk and safeguarding of the Individual. An Individual who has dementia may not want carers to come into their homes; they may not want anybody doing things for them and refuse the help. This can be frustrating for the carer however the carer may talk to the Individual in a subtle way and explain that he or she is not here to take over their lives but just here to help support them when they need help and just here to see that the Individual has had their medications.

The carer will find it useful to read the Individuals notes and care plan and get as much information as possible on the Individual. The carer will have to reassure the Individual and try and gain their trust. The carer may ask the Individual if you could accompany them to the shops or to an appointment

etc. The Individual must be allowed to take risks however if the risks look like they are dangerous or appear to be harmful we must explain the reasons to the Individual. If we cannot resolve the problem there and then, we must record the information and report it to the manager of the company supplying the service.

The manager will take the appropriate action with the relevant authorities.

The safeguarding of the Individual is paramount and we should never ignore potential high risks or dangers to the Individual, and we must work to policies and procedures and agreed ways of working at all times.

3. 3All organisations and service providers have a system for complaints and procedures these are legal requirements. Everybody has the right to complain about poor quality services, services not being delivered, services that Individuals need but are not being supplied, conflict with carers, service providers.

The Individual will have a document of complaints within their care package. The document should be clear and informative on how to make a complaint. The document will state who the complaint should be made to and timescales for when the complaint will be dealt by. If an Individual with dementia wanted to make a complaint I would support them and if they wanted I would read the document to them and support them in filling out the form. If the Individual with dementia didn't have full capacity to fill out the form I would liaise with the next of kin, family members or advocates.

I would inform them that the Individual would like to make a complaint and if they would like to help the Individual to fill the form out providing the Individual gave consent. I would explain how the complaints system works and when they would receive a response to the complaint. I would inform my manager that the service user or service user's family have made a complaint and I would take the complaint in an addressed envelope to my manager as soon as possible. When handling a complaints document with an Individual with dementia I would work within the Mental Capacity Act 2005.

I would explain to the Individual and the next of kin that the document is confidential and that it will be dealt with in a professional manner and that the complainant has nothing to worry about regarding the complaint and explain that it is their right of choice to complain. I would also explain that whilst complaints are being dealt with it makes the service user resolve the problems and also it is of benefit to the organisations in ensuring the problems don't occur again and that they get it right first time and this will have a positive impact on the organisations.

If a carer wanted to make a complaint about another carer they would follow the same procedure in filling out the document and they would take it to the manager. The manager would explain that in making the complaint it does not jeopardise their employment as they have a right and choice as whether to make a complaint. The manager would work towards resolving the complaint in a professional manner so that the employees can move forward and be happy in their work.

## 4. BE ABLE TO MAINTAIN THE PRIVACY DIGNITY ANDRESPECTOF INDIVIDUALS WITH DEMENTIA WHILST PROMOTING RIGHTS AND CHOICES

From apersonal experienceof supporting an Individual with dementia to maintain privacy and dignity, I have found that the more I get to know the Individual and them getting to know me the easier it has become for both of us to feel comfortable about maintaining privacy and dignity. Personal care and hygiene is a key factor. We should support the Individual to maintain their personal hygiene and appearance and their living environment to the standards that they want. We should respect their choices and decisions of choice of dress, hairstyle etc.

We should let the Individual with dementia make own choices and decisions. We should not make assumptions about standards of hygiene for Individuals. We should respect cultural factors and take them into consideration when supporting the Individual. Supporting the Individual to have a clean appearance and pleasant environment is good for the Individuals self esteem. Supporting female Individuals with dementia helps them to keep their home nice and clean and helps towards maintaining their dignity and self respect.

Supporting a male Individual with dementia, he may need support with shaving, maybe prompting the Individual to shave will all it will take and the Individual may go to the bathroom and have a shave and this will allow him to maintain his dignity and respect for himself. Supporting an Individual to have good hygiene will also reduce the risk of infection and promote well

being. We should ensure that the Individuals personal preferences are respected as well as their choice in how to support them.

Personal hygiene can be of many aspects, washing, bathing, showering, denture care, oral hygiene, foot care, hair care, grooming, nail care, toilet care, continence needs, dressing and undressing, laundry and housekeeping. We should treat every Individual with dementia with respect like we would anybody else. We should provide a person centered approach towards their care, putting the Individual at the centre of care.

Communicationshows how we respect the Individuals and this will help maintain their dignity and respect.

Privacy is also a key factor for an Individual with dementia; privacy must be respected at all times. We should respect privacy where people have personal relationships and sexual relationships. We should always ask permission and knock before we enter an Individuals personal space. We should get permission before accessing Individuals possessions and documents; we should provide space and privacy for Individuals private conversations. We should make sure the Individual receives their personal mail unopened, we should always pull the door too if the Individual is getting dressed or undressed and doesn't require support.

We must comply with the Human Rights Act 1998 as this gives the Individual the rights for respect, dignity, privacy and a private family life. Individuals with dementia should receive care and treatment in a dignified manner that does not embarrass them, humiliate them or expose them. Legislation states

that the Individual with dementia are to be treated as equal to everybody else. If an Individual with dementia had a toilet accident or was having regular toilet accidents, I would support the Individual by assuring them that it is ok and that it doesn't matter and that it can be cleaned up.

I would encourage the Individual to go to the bathroom whilst still assuring them. I would close the bathroom door and support the Individual to take off their soiled clothing and prompt the Individual to maybe shower or have a bath or a wash whilst still ensuring them everything is ok, I would encourage the Individual to have a bath in privacy that's if they didn't need support with getting in the bath or shower, I would let them wash themselves in privacy and when they had finished I would knock on the door and ask if they were ok and support them to put clean fresh clothes on so they feel fresh and clean again.

If the problem was ongoing I would report the problem to my manager as the Individual may need extra support and may need continence pads or pants, I would also discuss this with the Individual in a subtle way. I would work to policies and procedures and agreed ways of working and adhere to professional boundaries.