

Advocacy Script

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What is advocacy?

So what is advocacy? Well it means to defend. To stand up for. Now there is advocacy where you may be standing up for or supporting someone and there is self-advocacy where you are standing up for yourself.

In your work in healthcare, some people are able to stand up for themselves and others are not. This is important as one day you may need to be there for them or maybe you may want help yourself. This would mean you could call on the services of an advocate.

Slide 4 Types of Advocacy

Now let's look at advocacy in more depth and explore the different types of advocacy and when they would or could be used.

- Firstly there is Self-advocacy. I mentioned it in the last slide as being able to stand up for yourself. It is always best to be your own advocate but this is not possible if you don't have the information.

However there are many other situations where you need to stand up for yourself or your rights. It could be in a relationship, or at work, or an appliance you have purchased that has failed and covered under the consumer guarantees act. So you see there are many times in your life where you need to stand up for yourself but if you can't do this then you may call in a person to be an advocate for you. This could be a professional person or a friend or family member.

Now let's look at some other forms of Advocacy.

- There is Peer Advocacy which means you may want to help a colleague or friend who is going through something that is similar to what you have gone through. An example of this maybe you meet up with a person who has breast cancer. You may be a breast cancer survivor so you may offer to be a support person or an advocate for her as you have been through it yourself. Another example is you may have experienced being bullied so you may support a person who is going through a similar experience. If this happened at work, your friend may ask you to come in and be a support person for him/her in a meeting. You may also be asked to be a support person at a disciplinary meeting against a colleague.

Slide 5 Types of Advocacy

- Then there is Best Interest Advocacy which means that someone else has the best interest of another person in mind because they are unable to make a decision for themselves. Now this could be for someone who is mentally impaired or have mental health issues so they need someone to be there for them to act in their best interests. This person, acting on the best interests of someone else, would have to consider all aspects of care that is needed or being considered and make an informed decision on the correct course of treatment. Examples of this is a parent for a child or a person who holds enduring power of attorney for someone who has dementia or some other mental illness
- Now Statutory Advocacy occurs when a person is appointed by a court as a Welfare Attorney for a person as the judge believes the person is not able to make decisions for themselves. For it to go to the courts a health professional will need to apply to the court and supply information as to why an advocate should be appointed. When the judge hears all the information, he/she will make a decision on whether an advocate would be appointed.
- Then there is Crisis Advocacy. This occurs when a person is at risk and two people, one paid like a mental health support worker and the other unpaid like a family member can advocate for a person when or if a crisis occurs. Now an example of this may be for a person with a mental health condition or someone is in a coma following a stroke. This type of advocacy is not set in place for a long period of time, but something that will be necessary immediately to keep a person safe or to provide immediate care to help get them well again.

Slide 6 - Types of Advocacy

- Now Professional/Specialist Advocacy is advocacy from a solicitor or a specialist advocacy service. These people know what your rights are and are there to stand up for you in cases where you feel you have a grievance.
- Political Advocacy is where the government is lobbied on behalf of a group of people who have a point of view they want to get across and to facilitate change. An example of this may be if a Council wants to make changes to city plans, and a group of people or a person is against the plan so the group or person will get a petition together where people can sign their name as agreeing with the opposed group or person. This petition is then presented to the council for them to take notice of what the public are saying. Another example is where the public want the government to make some changes in an area and want to force a referendum. A referendum is where everyone can have their say and is usually held in conjunction with a general election. This could be something like wanting to change the national flag or the electoral system.

Slide 7 - What is the role of an advocate

The role of an advocate, is to

- Listens to your concerns.
- Gives you information about your rights.
- Help you identify and clarify issues.
- Help you to explore the options available to assist you to resolve each issue.
- Support you in the actions you take to resolve your concerns

Now you may say thank you for your help and manage the whole process by yourself which is self-advocacy or you may say, I can't do this on my own, can you help me which is asking for the services of an advocate.

Now it is important for you to know that an advocate does not make a decision for you unless it is a court appointed advocate. An advocate is there to help you solve your complaint or issues. Neither is an advocate and investigator of your complaint or a mediator to el settle your complaint. They are there to support you, encourage you to take action which may mean to lay a complaint but overall to help you reach a resolution about your concerns.

Slide 8 Self Advocacy

When we talk about self- advocacy it means that a person is able to stand up for themselves as I mentioned in slide 4. Some people do not know how to do this. It may be because they have always had someone who has spoken on their behalf and they may have lost the skills to do it for themselves. Some people just do not know how to be their own advocate so they need guidance or assistance to do this while others are just not able to do it for themselves.

However you need to understand that, everyone has the right to be their own advocate and it is your job to assist them in whatever way you can so their voice can be heard. Imagine how you would feel if people made decisions for you that you could easily make yourself? So always bear this in mind in any care or support you are about to do. The way you can help is to give the person in your care choices and options and make sure they are explained to them in a way they can understand.

Slide 9 What choices and options could you offer?

So how can you do this?

Well options or choices may be as simple as “What time do they want to have a shower?” And let them make a choice as to the time, or it may be as complex as they want to lay a complaint about some treatment or service and don’t know how to go about it.

Now if they want to lay a complaint you could do something like provide them with a complaint form and help them fill out. You could also give them the names of the facility or organisation advocacy people they can contact. This information would be found in you policies or in the admission information booklet or you could ask your Registered Nurse, Supervisor or Manager who it they are. You may even refer them to the Registered Nurse, Manager or Supervisor for the client/resident to talk directly to them. These are some of the options you could come up with.

It may be that they want to lay a complaint with the Health and Disability Commissioner, so you could get the phone number for them.

It may be that they have a family member or someone who holds enduring power of attorney or even their lawyer that will be able to work with the client/resident to lay the complaint. The family member may request from you the number to contact the Health & Disability Commissioner’s office so they can get information.

Now if they cannot use the phone you may have to get in touch with an independent person to work with them – an advocate which as I mentioned earlier, you will find in the Policy Manual or in the Admission to Service Information book or sheet.

It could be that they are really unhappy but need an interpreter or if deaf a person fluent in sign language to talk to them.

So can you see why it is important for you to know what options people have so you can explain it to them so they can be their own advocate?

Being your own advocate is really important but unfortunately some people are really reluctant to complain. People often feel that they are at the whim of the organisation, that they have no rights but this is not true.

Under the code of rights they have many options or choices and it is your job to make sure they know them or where to find out what their choices or options are.

It doesn't matter whether you work in a residential care facility or a home care organisation every person in your care has the right to be their own advocate. As I said, being your own advocate is to stand up for yourself: to speak out free of reprisals which means they do not receive a punishment or less than satisfactory care.

Slide 9 What choices and options could you offer?

Mental health people have been empowered for many years to be their own advocate. They have been encouraged to speak up for themselves with support if they need it. I remember an incident in a home I was managing where a person had a history of antagonising or teasing people. She did this one day to a particular person who fought back and hit her. Now she wasn't actually injured but she came up to my office and demanded he be arrested and that I call the police. In this case, there were very few options I could give her as she was clear she wanted the police to come down. So I rang the police for her and they came down and spoke to her about it and sorted the problem out for her. When the police arrived I explained to them what had happened as she had explained it to me. No one had actually witnessed the incident so it was her word only. I then I took the Police down to her room for her to discuss it with them on her own.

Unfortunately the person who had fought back had no recollection of the incident as he had dementia but that didn't make any difference, I still listened to her and called the police and she felt she had been heard. She had been her own advocate.

So you see self-advocacy is the right of every person. It doesn't matter whether you agree or disagree with the person –it is their right. So you need to listen to them and give them choices or options and explain these choices and options so they understand them and communicate in a way that they understand, and if need be, provide an interpreter. If you do not do this they could feel disempowered which means they just cannot stand up for themselves – they give up. See slide 13 where I discuss some of the likely behaviours you may see when a person feels disempowered.

When a person makes a choice, you have to respect it and give them whatever support they need. You need to ask them how much support they would like and what would this look like? For example they may want to write a letter of complaint but they have difficulty writing. You could ask them if they would like to dictate to you what they want to say or you could offer to get them a paper and pen for them to write down what they want to say in the letter or you could call in an independent person, an advocate to do it for them. You could offer to send the letter with a covering note from you, if it was appropriate and get the person to sign both letters. So there are many options here you can offer a person so they can make a choice.

Now I know that in some countries people don't have choices or options to speak up for themselves. If you come from a country where this happens, you do not have the right to apply those practices of your chosen country. You have chosen to live there and you have to abide by the laws and customs of that country. If you are ever unsure, you must ask your RN or Manager to clarify them for you.

A final word of warning though. As a caregiver, it is not appropriate for you to be involved with a person in your care. You do need to know your limitations as you could find that it may all come back on you. My suggestion is, always refer to the Registered Nurse, Supervisor or Manager any complaints that may come up. Don't get out of your depth as it could have serious consequences for you if you become over involved with a person. So know what self-advocacy is, apply it in your everyday work, and when it becomes too complex, refer it on to someone else.

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Categories of Advocacy

There are two main categories of advocacy. These are Case and Cause or systemic Advocacy.

Case Advocacy usually applies to an individual and to a specific case concerning a person. The person may manage it themselves as a self-advocate or ask the assistance of someone else to help as in an Advocate.

This is what applies to people using the health system. They may be unhappy with the way they have been treated by a hospital, staff in a residential care facility or a homecare worker. They may become their own advocate and write a complaint or call on management to voice their concerns so they are sticking up for their rights or a client in your care may complain to you about the care they have received by another support care worker or caregiver. They may request that you be their advocate, to act on their behalf but you need to be careful about this. It may not be appropriate for you to be a formal advocate for the person in your care but you can be an advocate for them by reporting it to your manager. You have an obligation to do this.

The manager may contact someone who can offer advocacy advice and get them to come and visit the person. Each healthcare organisation be it residential or homecare, will have a list of independent people who can be called upon to act as advocates for people. But as I said, you are an advocate for your client or resident and you must document it in case notes or your own notebook and report the concerns of the client or resident to your Manager or RN.

Cause or systemic advocacy on the other hand is where a group or an individual who wants to bring change to structure, systems, policy or legislation. This form of advocacy acts on behalf of a group of people who want to influence change i.e. Political Advocacy

Segment 2 Slide 1

To understand advocacy you also need to understand empowerment and disempowerment so in the next slides I am going to discuss these and what they mean.

- What is Empowerment
- Disempowerment/Empowerment Continuum
- Results of being empowered
- Effects of power imbalances
- How to empower people?

Slide 2 Empowerment

If we look at advocacy empowerment, we would get this definition .. to assist or act on behalf of a consumer. It believes it is better to equip and support consumers to solve their own problems than to take over their problems and fix them on their behalf. By equipping consumers with skills, knowledge and support they will know what to do if ever a similar situation occurs and they will be able to handle it themselves.

So empowerment means to really give power to.

To assist a person to handle the situation themselves,

To enable them to take control and stand up for themselves.

However it may mean for some reason the person does not have the capacity to stand up for themselves so consumers permission the advocate may stand up for a person them. In this case the consumer may feel empowered by the advocate doing it for them.

Slide 3 Disempowerment/Empowerment Continuum

If you look at this Continuum or model on the screen, you can see that at one end there is disempowerment and at the other is empowerment and there is a big play ground in between. So let's apply it to you. When people take your power away and do everything for you, how do you feel? Do you feel empowered and in control or disempowered and not in control? Well this is "doing for". **If you feel disempowered, it is really hard to be your own self-advocate. Standing up for yourself is almost impossible.** It isn't a very nice place to be in when you can't speak up for yourself but if you had a support person as your advocate, you would be able to do so. **To be your own advocate you have to be empowered.**

Now if you feel disempowered then you may need the help of an advocate **so you can be your own advocate.** This person would work with you and help you to make a decision by supporting you and explaining to you what your rights are and the avenues you can take to get your rights recognised. In essence the advocate will be empowering you to take charge of the situation by giving you information. This is "doing with" **for you to be your own self-advocate**

Next there comes the coach. This is someone who is helping you find the information and encouraging you to take action, if that is what you would like to do. What is important here is it has to be your decision and not that of the advocate. This is not the role of the advocate to bully you into taking action **as this will disempower you so self-advocacy would be really hard.** You actually need to want to take action so you need a coach to explain to you how you can do it **which empowers you towards self-advocacy.** Working with a coach may mean that the advocate helps you to set yourself goals to work towards so you can achieve what you want to achieve. A coach helps you develop skills to do it yourself.

Finally there is the mentoring stage. This means you know you have someone to call upon to help and support you so you can ask questions on what to do **and be empowered.** Having a mentor is like having a big brother or sister there beside you but you do all the work and handle it yourself knowing that there is someone you can call on if you need help. A mentor is a wise and trusted counsellor or teacher.

Slide 4 Results of being empowered

One of the most important things about feeling empowered is being in a **state of power.** People who are empowered **feel they can defend themselves, feel more confident and therefore air their concerns and complaints.** An empowered **person feels good about himself or herself and are more likely to ask for what they need.** They are more likely to make choices and are happy and outgoing. **This fosters self-advocacy.**

Slide 5 Effects of Being Disempowered

When a power imbalance occurs people may become very passive and play the victim. But in some cases people may behave in the opposite way.

Often people in your care do not think they have any power. They are at the mercy of the care being given or the organisation looking after them. This is not so. Remember, the person in your care is actually paying your wages. You need to look upon your work as being employed by them. The organisation is merely the filter for the money to be passed on to you for the work that you do because the care you provide is paid for through the taxes the person has paid throughout their life time or personally themselves. This money comes to your employer via the government or by an account sent to the person or both. So they are paying your wages.

You need to be part of the culture that empowers people and doesn't disempower them. Disempowerment can have devastating effects on a person health. A disempowered person is more likely to become depressed and withdrawn. They become very apathetic which means they are lethargic, indifferent or dispirited. They are unlikely to speak up for them self and suffer from feelings of worthlessness and helplessness, that they don't matter. That no one listens to them anyway. They may be afraid and feel very vulnerable which means to feel weak and defenceless.

They may not answer you when you speak to them or may not know what to say so will say nothing. They won't stand up for themselves and are dependent on you or someone else to make decision for them or speak for them. They may feel a victim. These are the more common effects of a person who is disempowered.

However in my experience, it is possible for some people who feel powerless, to behave quite differently. They may cry a lot, demand attention, and be in your face all the time wanting you to do something for them and they may whinge which is to moan or whine and bleat. Some people may be downright aggressive in the way they speak and their actions. They could even be agitated which is restless, nervous or distressed. They can even be totally irrational with crazy, ridiculous or outlandish in their demands. These are all in an attempt to gain back some power in their life. While these behaviours are less common, it is important to know that people behave in many different ways when they feel they have no control of a situation.

Slide 6 How to empower people

It is about **validating a person**. By that I mean to listen to them and acknowledge them. You do not have to agree with them. You just need to know that it is important to the person in your care and it has an effect on them emotionally. You need to validate the emotion but sometimes you don't know what the emotion is? They haven't communicated it to you. Now if they have laid a complaint, they could be angry or upset so you need to validate the emotion. To do this you could say "I understand you are angry". Don't jump in and justify or defend – just validate them. If they were not upset or angry they would not have made the complaint in the first place. You need to honour this.

So **speak kindly** to the person. Let them know you care about them; that they are important and they matter. Never raise your voice with people. Keep calm and **speak kindly** to them and **listen to their concerns**. Note down on a piece of paper if you can. Reflect back to them "So you are angry aboutAnd reflect what they have told you they are angry about.

For example a lady may have rung her bell and when you get into the room you find her crying and very upset. She may be shouting as well and you cannot understand what she is saying. So the first thing you could say is "You look angry to me. Can you tell me what you are angry about?" Then wait for her to answer. This is validating the person.

Next you wait for her to calm down so you can understand what she is angry about. She tells you "I've been left on the toilet for such a long time and have a sore bottom"

You say "So you are angry because the caregiver forgot to come and take you off the toilet?"

"No" she says, "Because my bottom is sore"

You may then say "Your bottom is sore and painful because you sat on the toilet for a long time"

She says "Yes my bottom is so sore now"

So the issue may not be that she was left sitting in the toilet for a while, the real issue is her bottom is sore and she is in pain. So you can see what the problem is now and you can attempt to help relieve her pain.

Now you do not know how long she was left on the toilet or indeed if she was left for a long time at all. So don't make a judgement. Yes it could be she was left for a long time, but it could also be that she is frail and debilitated so any time sitting on the toilet would be too long. However you do document it in the progress notes and you pass it on to the RN or manager that she was upset and why.

Now I know that some people can complain a lot and you may feel it is making life difficult for you, but just think, if they were happy they wouldn't complain. On the other hand, some people won't complain at all. This could be through fear of reprisals or punishment because if they did stand up for themselves they may not get

good care. Now you don't want to have anyone in your care that is afraid and won't speak up. It is your role to make sure that they feel safe and able to voice their concerns free of judgement or consequences.

When a complaint is received you need to work with the person to find a solution to the problem. Do not get caught up in justifying or defending the situation. If you do not know how or what to do in a situation, then, excuse yourself from the conversation and report it to your RN or Manager and get them to deal with the problem.

The best outcome for the person will always come from them being able to find their own solution. If they do this then they are empowered as it will be their decision. If you do not have the skills do this, it can make a situation worse and they blame you for what has happened so know when to hand it over to someone else more skilled than you. Your manager or RN will know how to handle it.

To empower a person means that you **speak kindly to a person** and do not talk behind their back. That means that if you have an issue with someone when you are talking to them you keep to the problem at hand and don't make it personal. Putting the person down is really destructive because it disempowers them. There is nothing to be gained by damaging a person and lowering their self-esteem. People are more likely to make more mistakes if they feel inadequate and useless. Just think of a time when someone put you down. How did you feel? Did you feel like you could defend yourself? Did you get into an argument with the other person saying nasty things about the other person? Did you feel empowered or disempowered?

Slide 7

Be respectful which means to be polite and courteous. It is to be positive about them and not to prejudge them or allow your own prejudices to influence the way you behave towards them. Everyone has the right to feel safe and treated fairly and feel accepted by others. I know sometimes it can be hard if you have had a trying day, but in the end it will pay off. Always put yourself in the other person's position.

Be encouraging. Help people to help themselves. Give them the support and encouragement to speak up or to deal with their own issues with your support. Using words like, "I can help you with this problem. Let's break it down into bite size bits and see which is the most important issue to look at first is." By doing this it is not making the problem too big for them as some people can be totally overwhelmed by the situation they are in. "I will help you and be here to help you through this. What is the biggest issue? "

Offer praise Tell them that is okay to complain. It is their right and you will do what you can to help them. It is not always an easy thing to do or say what is really upsetting you. Remember this is not about you. You are helping the person in your care to take a stand for themselves.

Give choices some people get stuck on one point and find it difficult to move past a certain stage so you could suggest things they could use. For example they may not know how to go about sorting out the issue. So by digging down to the real issue that is worrying them, you could then offer options. For example if we take the incident with the lady with the sore bottom. You could say "how would you like me to help you?" If they don't know you could then say "Well I could go and get the Registered Nurse to come and see you, or I could help you on to your bed so you are not sitting on a hard chair or I could gently rub some soothing cream on to your bottom. What would you like?" This is about giving people choice. So they have 3 options to choose from.

Now I have used an example that is easy to understand. There may be more complex issues but the point I am trying to make here is when a person is validated, listened to, respected, given praise and choices, people are empowered.

When a person is empowered they can do anything. We all need to have someone to be our champion at times and that could just to have someone to walk alongside you. Think about times when you may have felt disempowered or even empowered.

Slide 8

Communicating clearly is the best way to empower people to be their own advocate so you have to use a range of methods to do this. So let's look at these now

Firstly let's look at words. Words are very powerful but you need to use **words a person** can understand. It is no use using medical jargon when they have no idea what you are talking about. It is no use using English when the only speak Chinese. What do you do when someone uses words or speaks in a language you don't understand? Do you say I don't know what that means or what you are saying or do you not want to show your ignorance and show yourself up by saying "I don't know what your mean or are talking about?" Well many people don't put their hand up and say they don't understand. So words have to be in **simple** language. It may mean you have to **write the** words down for them to read if they are deaf or use **sign language and gestures**; or you may need to bring in an **interpreter** to speak in their own language.

It may mean that you need to **draw pictures** so they can see what you are trying to explain or it may mean you have to create some **signs** that are universal and easy to understand maybe draw a flow chart. You may also use **computers or electronic devices** to help communicate.

So you see you may have to use a variety of different ways to ensure the person understands what you are saying or trying to say to them. Communication is about the giving and receiving of messages. If you are giving a person a message that they cannot understand, it can be very frustrating for both the receiver and the sender so think how best to communicate with a person.

Slide 9

So if we summarise the continuum in slide 9 some people feel more empowered by having an another person speak on their behalf. They could then talk to them in confidence about what has happened and be given information on what they could do about it. It may mean they need the advocate to do it for them if they didn't have the ability to do it for themselves like if they had diminished capacity. This could be an intellectual or mental disability but it could also be they feel that if they spoke up for themselves they may suffer some consequences – they are afraid. Now no person should feel unable to express their feelings but if they do, an advocate can be very helpful for them and they may want someone to do it for them.

On the other hand a person may want an advocate to help write a letter as they don't have the confidence to do it themselves and want guidance as to what to put in the letter so the advocate may coach them and take it step by step and discuss what can be put in the letter. Or the person could have written a draft and they want the advocate to read through the letter and maybe make suggestions on how it could be written to get better impact before they send it. Once the letter is completed and sent, the advocate's job is done.

However a person may want someone to be around for a little while guide and teach them the process. This maybe an on-going relationship that may include the letter being written, attending any meetings that are arranged or some on-going relationship with the person.

As time goes on you will develop more skills and knowledge to be able to help people in your care. However one of the things you can do for your clients is listen to them and put them in contact with the right people to help them with their complaint or area they are seeking help in. That is being an advocate too.

Remember when you are caring for a person you are always their advocate. If you see or hear things going on that is disempowering a person, then you must take action. It could be overhearing a conversation a person is having with a family member that is abusive. It could be someone trying to coerce money from them. You

need to report this to someone immediately. Write in in the person's notes, file and incident report or in your own note book if working in homecare. Call your supervisor or manager immediately. If you don't you are not helping a person solve a problem, you are part of the problem. How would you feel if you were on the receiving end of abuse and no one came to your help? Always write down the facts of the situation including time, date, location and what you heard. Do not put your own interpretation into the incident.

Never assume a person is unable to do some things for themselves. Encourage, support, coach, mentor or work with a person to be the best they can be. This is what an advocate is.

Always remember, if you are writing a letter always focus on the facts. Don't get lost in the story or make assumptions. Just keep to what happened, when it happened and what happened as the result. By focusing on the facts you remove all the emotion out of the letter. While you may well be upset, emotions get in the way of finding a solution. It is no good saying I was so upset with what happened that I cried all night if the receiver of the letter didn't know what had been done that made you upset and cry all night.

An advocate as a mentor or coach will be able separate themselves from the emotion in the complaint and uncover what the actual issue is and this is how the letter should be written or offer options for the person.

Finally it is important that you do not step outside your scope of practice or skill level. If you do not know what you are doing it could have dire consequences for both you and the person you want to help or has asked for your assistance. If you are unsure, always pass it on to your manager. They will know what to do.