

Communication and Mealtimes Toolkit

Helping people with
dementia to eat, drink
& communicate

A GUIDE FOR CARERS



Compiled by Rebecca Kellett and Colleagues
Speech and Language Therapy Adult Service, NHS Dumfries and Galloway

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INTRODUCTION

BACKGROUND

The care of people with dementia is now high on the health care agenda in Scotland. There has been an increasing awareness of the need for improvement both in the quality of care and in the amount of care available as the number of people living with dementia rises.

This has prompted many exciting initiatives including the Charter of Rights for People with Dementia 2009, the National Dementia Strategy 2010 and the Standards of Care for Dementia in Scotland 2011.

This toolkit was inspired by the Dementia Champions training, and by the “Interests and Activities Toolkit for use with People with Dementia” published by the Occupational Therapy Service.

The toolkit is based on the day to day experience of clinicians, who meet carers wanting straightforward, practical advice about eating, drinking and communication. It describes solutions rather than problems, assuming people will refer to the numerous excellent resources already available for more detailed background information if they wish.

THE TOOLKIT

This toolkit is intended as a brief practical guide for those living and working with people with dementia, at home or in a care setting, when the dementia has reached a stage where significant support is needed.

There are recommendations on how to focus on **person-centred care** with particular reference to communication and mealtimes. Person-centred care underpins all the advice given.

The first section is about communication. It begins by suggesting ways of helping a person feel secure, and describes how to compensate for their loss of memory. There is guidance on having conversations in a way which helps the person feel valued and feel like themselves, and advice on how to communicate when language skills diminish. Making use of environmental cues to orientate and inform is an important part of caring for people with dementia, so ways of doing this are highlighted.

Examples of life-story work are included to help give you ideas to develop your own.

The second section is devoted to looking at mealtimes in detail. Although problems with eating and drinking are common for people with dementia, many of these can be prevented by careful management. For example, leisure activities which motivate people and encourage social interaction during the day have been shown to help mealtime behaviour.

Advice is offered on how to prepare a person for mealtimes and how to provide the most suitable environment. Oral hygiene, posture, how to boost intake and assisted feeding are covered. Texture modification is touched on and there is a chart of foods which are most likely to cause choking, with some suggested alternatives. There is information about when specialist advice should be sought, and there is also advice about what to do when a person with dementia becomes unable to eat and drink reliably.

Mealtime advice is summarized in a prompt-sheet which can be photocopied as a poster if wished.

At the end of each section is a care-plan which gives an opportunity to reflect on how the advice is followed with each person.

PERSON-CENTRED CARE

Person-centred care is the guiding principle for working with people with dementia. The key to this is to try to see the world from the person's point of view, and give them an environment which is familiar, predictable and safe. This cannot be achieved without a detailed knowledge of the person's background, and their physical, social and cultural or spiritual needs. It is important that significant names, places and events in the person's life are known so that these can be used in conversations. All interaction should help the person feel valued, and give them as much control as possible over what is happening to them.

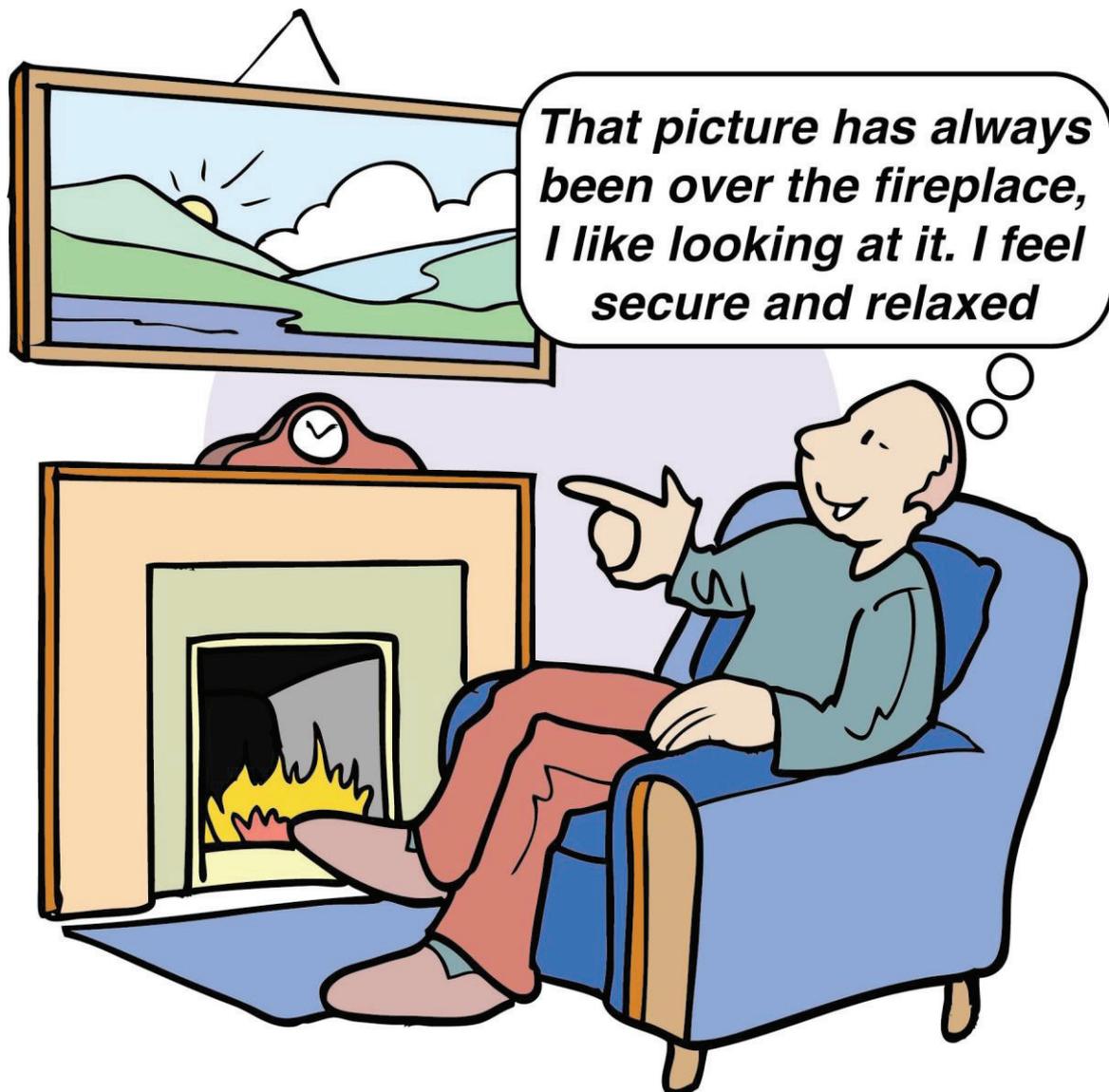
Person-centred care concentrates on the individual, and although general advice can be helpful, one size does not fit all. All guidance must be interpreted to suit the particular needs of each person.

Effective person-centred care has been shown to improve the quality of interaction between people with dementia and their carers, and reduce challenging behaviour. There is evidence that appropriate care improves eating and sleeping, as well as alleviating anxiety and distress. This in turn reduces the need for sedation and anti-depressant medication, which means there is less

risk of negative drug side-effects. The advantages are therefore wide-ranging and significant.

Person-centred care has no cost implication. It may involve doing things slightly differently, but the benefits more than outweigh any extra demands in time and effort.

This booklet is not an assessment tool, nor is it an instruction manual. Specific types or stages of dementia are not discussed as this information can be found elsewhere. Dementia often occurs in combination with other conditions which may require additional specialist intervention.



COMMUNICATION

It cannot be stressed enough that the key to successful person-centred communication is knowing as much about the person as possible. Integral to the carer's role is to:

- ❖ Look after their memories for them
- ❖ Provide their “comfort zone”

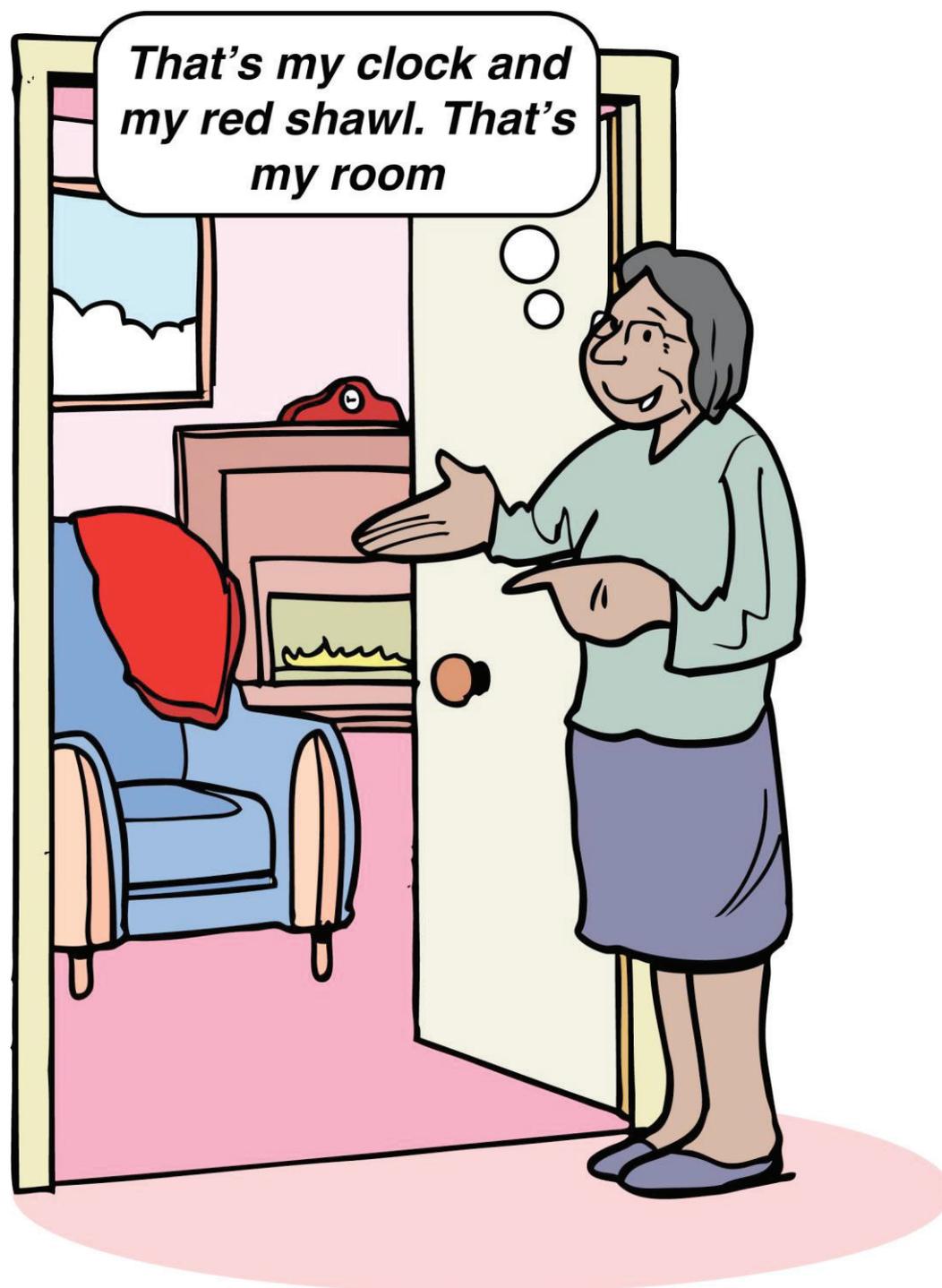
Try to find out what would make them feel at home, for example:

- Family photographs – an album, in frames, on a frieze or photo board, or in a “memory box”.
- A special shawl, scarf, cushion or blanket.
- A familiar newspaper or magazine, even if they cannot read it.
- A favourite radio channel or music track.
- Familiar packaging of food or toiletries (iconic brands).
- Tea-cosy or patterned china from home.
- Trinkets, jewellery, perfume or aftershave.
- Paintings or small items of furniture from home.

It is particularly important to think about this when a person has to move rooms, or move in to a new care setting. Plan in advance so that familiar items are in place before the person arrives.

Some care settings use a deep-box picture frame by each person's door with recognisable belongings inside. This helps the person identify their own room and feel comfortable about being there.

Familiarity and predictability are also important if the person has carers, and care rotas should reflect this.



PERSONAL INFORMATION

If you do not know the person, find out as much as you can from friends and family. This list is a guide to the information you will need to offer effective person-centred care:

Others:	
Important people - their name and connection to the person	
Important animals	
Mealtime:	
Drinks and snacks - when, what and where	
Familiar tableware - crockery, tablecloth etc	
Food likes and dislikes - favourite brands etc	
Mealtime routine - when, what and where	
Entertainment:	
Computer/ IT	
DVD's	
Music	
Radio	
Reading	
TV	
Me:	
Celebrations	
Daily routine	
Hobbies and favourite pastimes	
Holidays	
Preferences for clothing, hair, make-up etc.	
Proud moments	
Regular places visited	
Sad memories	
Special achievements	
Spiritual or cultural beliefs	
Work history	

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LIFE-STORIES AND MEMORY BOOKS

These are a valuable way of finding out about the person and looking after their memories. The person with dementia is much more likely to use and enjoy the finished product if they have been involved in creating it. Making it also gives great opportunities for interacting, making choices and sharing memories.

However, even if the person with dementia is not able to take part in creating their memory book, box, card, poster or notice-board, they may take great pleasure and pride in looking at it and showing it.

If family members can get involved, they are often the best people to provide material and create something special for the person. It can be very rewarding for younger family members to do this with their loved one. They may be able to contribute IT skills for instance, but can also learn about their relative and develop their relationship as well as their own communication skills.

Different presentations of life story suit different people or settings. Formats to consider are:

- a single sheet with small icons or pictures which show key people, events and pastimes (in one of the examples this is done as a time-line).
- a picture-book with more detailed written information which the listener can read with them and refer to.
- to keep their old family albums in the familiar format, but with names added to help listeners identify pictures.
- a box which includes objects as well as pictures and written information. This might include a badge from a former job, a prize rosette or trophy, a gift from a special person, a piece of handwork, postcards or letters with a loved one's handwriting.
- a notice-board with pictures, information and memorabilia.

Various examples are shown, but you don't have to use expensive dolls' house furniture or sophisticated computer programmes.

Pen and paper and a few photographs will do the job.

Whichever way the information is presented, carers should know what makes the person feel proud or happy. Revisiting proud moments helps the person feel valued and worthwhile.

Be aware of sad memories so that they can be acknowledged and understood, but steered away from if necessary.

Know the person's favourite activities or memories so that these can be used to divert them from negative or unproductive thoughts or behaviour. Use materials associated with their hobbies in conversations or activities, and select relevant TV programmes.

Be aware of beliefs or opinions which are different from your own and try to be sensitive to them.



What is important to Ken

Walking whilst being guided.
"When I walk and hold some ones' arm I can really stride out, I pretend I can see again."
I have to have things to do throughout the day, going out with somebody to guide me, practising my guitar and keyboard, being around people.
That people don't treat me differently because of my disability.
I am a keen Elvis fan and my most valuable possessions are my Elvis memorabilia.
I love to sit and chat with people especially about my younger days when I was a mechanic.
That people listen to me.
That I stay physically fit by keeping on the move in my flat.



How best to support Ken

People supporting me must have a sense of humour.
Don't move things about in my flat without asking me as I will not be able to find them due to my visual impairment.
Tell me what you look like.
Listen to me and chat with me so as we get to know each other.
Help me to do as much as I can myself.

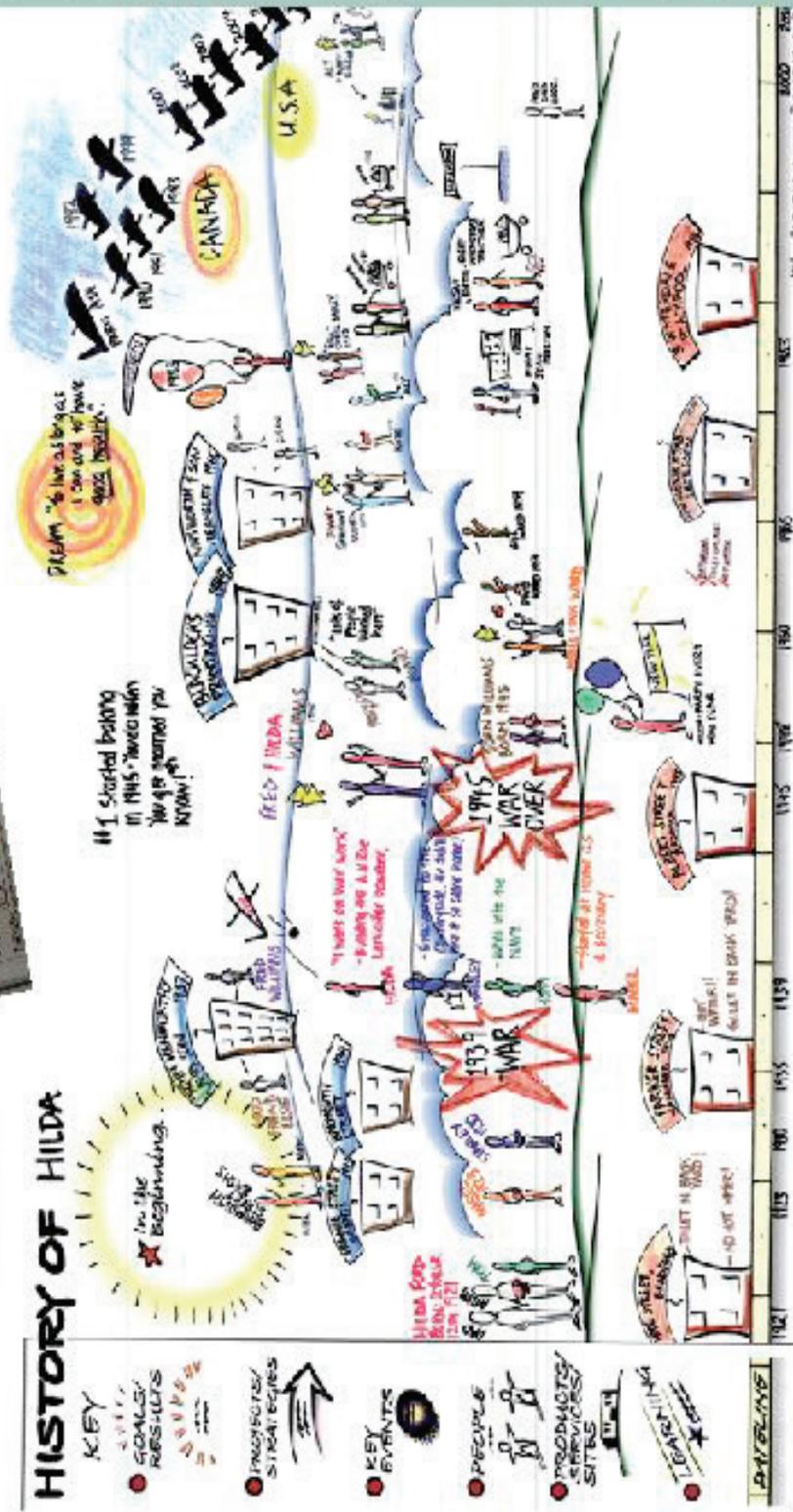
What those who know Ken say they like and admire about him

Good to spend time with.
Jolly and always game for a laugh.
Tells wonderful stories.



Ken

History of Hilda



Hilda Williams

Hilda is an inspirational woman, who is proud to be 87 and living in her own home in Blackpool. You would only need to spend a brief amount of time with her to feel the joy for life she exudes.

A film buff, her knowledge of the movies right back to the 1930s is incredible. She has travelled widely visiting her daughter Joan and her family, as their work has meant they have lived in many different countries. Her latest holiday photos are from Hollywood.

Hilda was talking with her great-niece, Babs, about how the world has changed and her hopes and fears around getting older. What really frightened her was that her memory wasn't as good as it used to be and that;

Some day I may not remember what a great life I have lived so far.

Babs and Hilda decided to spend a few hours together to capture Hilda's life on a graphic history map. This was the start, and now they are scanning in family photos to create a family history book as well.

Making a Life-Story Book

- here are some more suggestions

The purpose of a Life-Story Book is to help people get to know the person as well as possible. The book can be made up by anybody who knows the person well. The more they can contribute themselves, the better.

- Get a small photo album (6" x 4" or 7" x 5").



- It is good to begin with a photo of the person; one which they are happy with. Perhaps one from when they were younger.

	<p>This is me.</p> <p>I like to be called . .</p>
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- Put photos of family, pets and places of interest e.g. holidays, places where the person has lived, favourite places to visit, in the album.
- On the opposite page explain who / what is in the photo e.g. husband / partner / wife, daughter / son. Describe the occasion when the photo was taken.

	<p style="text-align: center;">This is my Family</p> <p>My HusbandMy Children</p> <p>My GrandchildrenMy Sister ...</p> <p>My Pet My Partner</p>
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- List things that your family member does e.g. favourite TV programmes, radio stations they listen to, what music they listen to, crosswords, jigsaws, bingo, card games etc.

<p>Likes</p> <p> I like a good joke and I love talking</p> <p> I love shopping</p> <p> I enjoy listening to music, especially.....</p>	<p>Likes</p> <p> I play Scrabble and cards</p> <p> I like reading books and magazines</p> <p> I like watching TV. My favourite programmes are.....</p>
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- List what activities the person does or did in a normal week e.g. Monday shopping, Saturday play golf.

<p>My Week</p> <p>Monday: I get my hair done </p> <p>Tuesday: I go on the bus to town </p> <p>Wednesday: Rest </p> <p>Thursday: Visit my friend </p>	<p>My Week</p> <p>Friday: Warm water swimming </p> <p>Saturday: Lunch club </p> <p>Sunday: Rest </p>
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- Make a list of favourite foods and foods disliked. Include preferred ways of preparing and serving.

<p>Foods</p> <p>Breakfast:   </p> <p>Snacks:   </p> <p>Lunch:   </p>	<p>Foods</p> <p>Dinner:   </p> <p>Puddings:   </p> <p>Drinks:    </p>
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- Make a list of spiritual or cultural needs

<p>My beliefs </p> <p>I like to pray / meditate</p> <p>I don't eat for religious reasons</p> <p>My culture forbids.....</p>	<p>These are the days I like to celebrate.</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>What I do..... </p>
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- Make a list of proud moments or achievements

<p>I am proud of:</p> <p>I came first in the cross-country at school when I was 15. </p> <p>I have knitted more than 60 jumpers. </p>	<p>I grew the best onions in my village </p> <p>I did my job for 40 years without a single day off sick </p>
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Anything can be included in the life-story book that helps the person with dementia tell you about themselves.

PERSON-CENTRED CONVERSATIONS

The language you use should be clear and straightforward without being patronising.

Look at the person, with your head at their level if possible.

Address the person in the manner you would have used when they were not affected by dementia. They will be aware of good manners. Make sure you know whether they like their surname, first name or another name to be used. For some people it may be helpful to say their name and introduce yourself every time you meet. This may feel repetitive but is worthwhile as it is reassuring.

Express one idea at a time. Make allowances for a limited attention span.

Allow extra time for them to get their message across, and judge from their reactions whether they like you to guess or make suggestions.

If the words do not make sense, try to work out the meaning behind the words.

Do not challenge or contradict. Lead the conversation around tactfully.

As the person's horizons get narrower, their thinking and communication becomes more limited. Abstract ideas become less relevant. Complicated decisions should be avoided. Open questions such as "What would you like to do today?", may become too broad. A choice between two options, and finally a Yes/No response to one option, may be more appropriate.

You may have to listen to the same stories, questions or concerns over and over again. Remember that to the person it is important that you react as though you are hearing it for the first time. Your familiarity with the topic may make it easier for you to think of a helpful response.

NON-VERBAL COMMUNICATION

This is about every aspect of the way you treat a person.

As language becomes less useful, other means of communication become more important.

Remember that people will recognise the meaning in your tone of voice even when the words have lost their meaning. They will pick up any sense of disrespect or impatience.

You may not always be aware how much your facial expression is communicating. It will convey interest, respect, friendliness, reassurance, humour and kindness. It can also convey, frustration, impatience or anger, so it is important to suppress any negative feelings while you are with the person. But a carer's role can be very demanding, and it is important to try to find space when you are away from the person to deal with stress and find the support you need. This will help to keep interactions as positive as possible.

Take care not to belittle, deceive or ignore. It is important not to talk across people. Even if someone cannot participate in a conversation going on between carers, they should still be included.

Smiling and laughing are good, but take your cue from the person and make sure they feel laughed **with**, and not **at**.

Avoid sarcasm, even if it is directed at something else, the scathing tone can cause pain.

For the person with dementia, making a contribution could be a form of communication: is there a task they can do, such as watering a plant or dusting?

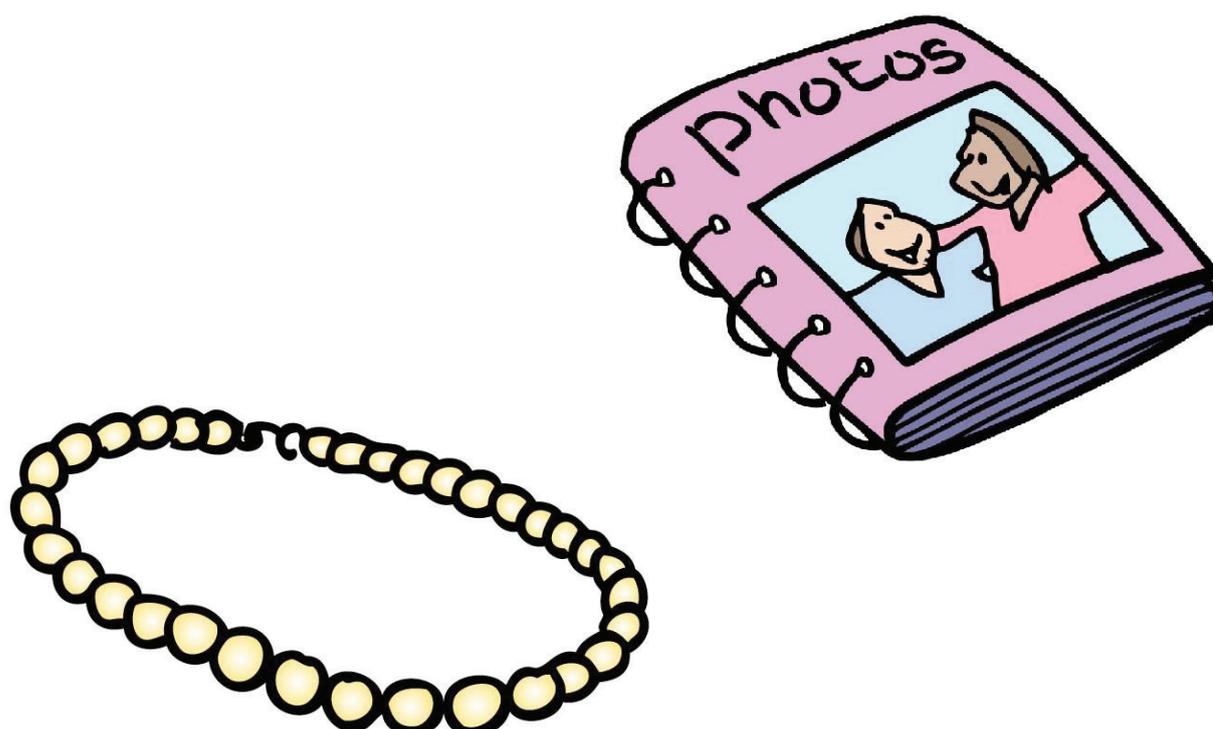
Allow the person as much choice and control as possible, for example where to sit and what to wear.

Remember that when speech has gone, appearance can become a person's chief way of communicating their sense of self. It is important to make sure that their style of dress, and the way they look, is what they like and are used to.

It is important to recognize that as verbal communication becomes less effective for them, feelings may tend to be expressed non-verbally. Anger may seem more extreme to you because it cannot be vented in words. A banged table or shout may come across to you as bad temper when only slight impatience or frustration was behind it. Be careful not to over-react as this may cause the behaviour to escalate. Anti-social behaviour must be discouraged, but this should be done tactfully, and the feelings behind it should be acknowledged.

In the advanced stages of dementia, even when a person is bed-bound and not responding to speech, communication is still essential to quality of life. Case studies have shown people participating in interaction with eye contact, noises, movements and smiles if the carer engages them in the right way. Try sitting quietly with the person and becoming part of their world by joining in with their noises, and their hand or facial movements. It may feel embarrassing at first but can have a very positive outcome.

Physical touch can be a significant part of communication, but also needs care. Personal space and dignity should be respected.



USING THE ENVIRONMENT TO COMMUNICATE

The way you manage the environment can be an effective form of communication. The environment can structure the day and introduce what is going to happen next.

At its simplest, this can be done in daily diary boards, clocks, calendars and notices. Labels on rooms or colour-coded walking routes can be effective.

For people who cannot interpret these, physical props and routines are important. Going in to a different room can signal a mealtime, or hearing the clatter of cutlery, smelling cooking or seeing the tables being set.

Having outdoor clothes brought tells a person they are about to go out. If they are going to an appointment, a photo of the person they are going to see or of the building can be helpful.

If there is to be a musical entertainment for example, looking at photos of a similar event, playing recordings, opening the keyboard or arranging the furniture can help to set the scene, so that it does not come as a surprise.

At bedtime, setting out the nightwear and toiletries, closing the curtains, giving a bedtime drink, can all help to communicate what is about to happen. Leaving the bathroom door open with the light on is a form of communication which may help a person with dementia find their way to the bathroom at night.

Interior décor can be used to draw attention to particular doors or places. For example, the door to a private cupboard you do not want a person to look in could be covered with wall-paper, but the person's own door could be a colour that stands out. In a care setting, residents' doors and rooms can have their own individual colour schemes. Red is sometimes used for bathroom door frames and toilet seats to draw attention and help the person identify where to go. Good lighting is always important to help people interpret their surroundings.



COMMUNICATION CARE-PLAN

Name:	Filled in by:	How this is achieved	Date:
	I have familiar things around me		
	I know who will be caring for me		
	Detailed information about me is known and available to all carers		
	My life-story, memory book or equivalent has been developed and is available		
	Memories are used in communication		
	Conversations are person-centred		
	My non-verbal behaviour is valued and used in communication		
	The environment facilitates positive communication		

COMMUNICATION CARE-PLAN - example

Name: <i>John</i>	Filled in by: <i>Lee</i>	How this is achieved	Date: <i>01/01/12</i>
I have familiar things around me			<i>John's wife, Mary, has brought in some cushions and some framed pictures which are on the wall. He also has a special china mug.</i>
I know who will be caring for me			<i>There are three key workers, Joe, Mia and Lee, who look after John in rotation. The names and photos are always put up on the board.</i>
Detailed information about me is known and available to all carers			<i>Mary has told us a lot about John and we have filled in his personal information booklet. Time is allocated to look at this and remind ourselves of details.</i>
My life-story, memory book or equivalent has been developed and is available			<i>This is a work in progress! All sorts of people are contributing so we have used an A4 ring binder and add sheets. John loves looking at it with his wife and other visitors. There is usually time in the afternoon for one of us to spend some time talking about it with John.</i>
Memories are used in communication			<i>John also has photos of special occasions in his room which we often refer to. We are all familiar with his life-story book so often talk about what is in it and point out the pictures.</i>
Conversations are person-centred			<i>We take care not to talk across John. He likes people to call him "partner" because of an old family joke.</i>
My non-verbal behaviour is valued and used in communication			<i>When John starts rocking we know he is in pain. He also taps the table when he wants a bit of company so we respond to this.</i>
The environment facilitates positive communication			<i>John is very aware of his clothes so we use these to signal different stages of the day and events. He has a special tie for church. Slippers mean he is staying in, but he likes to put smart shoes on for special visitors, so he knows someone is coming when we put them out.</i>

EATING AND DRINKING

AVOIDING OR PREVENTING PROBLEMS

It is always best to identify the factors which are likely to lead to problems, and take any possible action before complications develop.

The people with dementia most at risk of eating and drinking difficulties or malnutrition are the ones who:

- only require moderate assistance with self-caring
- are in a care home and have few family visitors
- have poor oral hygiene
- are on multiple medications
- smoke

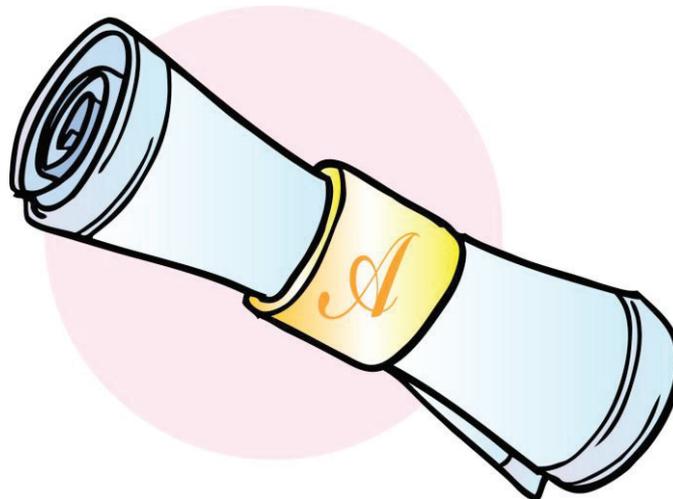
A person-centred approach should mean that these people are closely monitored, and appropriate action is taken to reduce the risks.

Action can include:

- monitoring to ensure optimal nutrition
- making efforts to improve social participation
- encouraging visitors in care settings and enabling a family member or close friend to join in with mealtimes
- increasing oral hygiene
- improving pain management
- reviewing medication
- checking for signs of infection

Problems vary according to the type and stage of dementia, and can be associated with both cognitive and physical factors.

Not all problems can be prevented, but all people with dementia will benefit from careful attention to their mealtime needs.



PREPARING FOR MEALTIMES

When we plan a meal for ourselves, probably the first thing we think about is **what** we are going to eat.

For a person with dementia, other factors may be just as important and need to be thought about and planned.

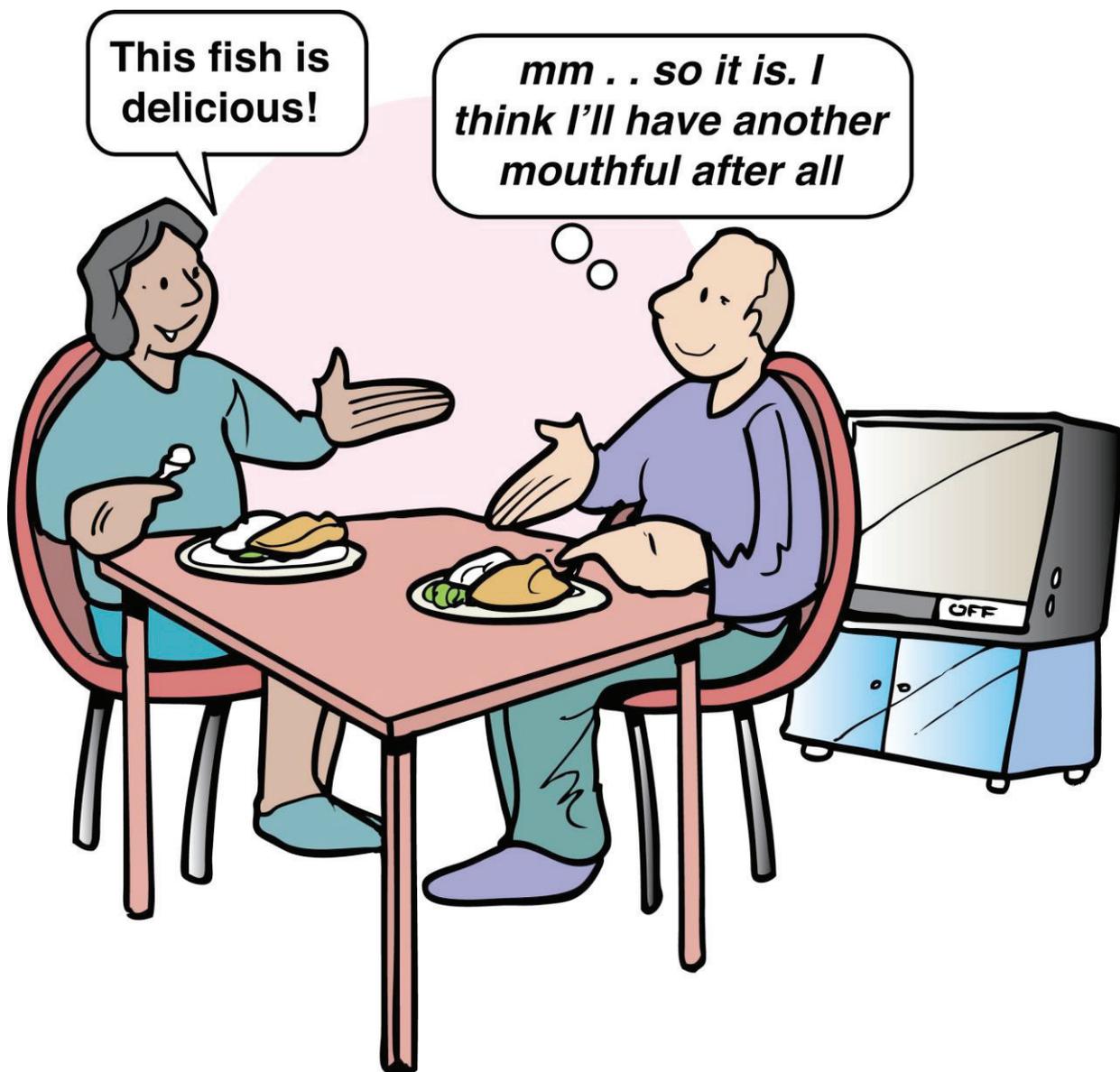
- Does the person have a best time of day for eating? For example, if they eat best in the morning, can breakfast be their main meal? Are they better eating little and often? If possible adapt your mealtimes to the person rather than trying to make them fit in with your routine. This flexibility may not be achievable in a residential setting where different interests will conflict. Try to find a workable compromise.
- Be aware if concentration, appetite, or ability to eat is affected by medicines and plan doses around mealtimes accordingly.
- Make sure pain is treated well in advance of a mealtime.
- Make sure the person is comfortable before a mealtime and does not need the toilet.
- Try to make sure the person is as calm and settled as possible before a meal, and do what you can to resolve any anxieties.
- Sight, smell, hearing, and taste have a huge role in stimulating the appetite and the swallowing mechanism. Ensure glasses, hearing-aid, dentures are clean and in use so that all senses are operating as well as they can.
- Check that dentures fit well.
- Routines which build up to a meal – setting the table, going from one room to another, can improve appetite. Involve the person in preparation as much as possible.
- Talk about what they can smell before the meal and keep talking about the smell and taste of the food as the meal progresses. Use strong flavours or a change in flavour or temperature to stimulate alertness if needed.
- Try to make the mealtime as much like a meal at home as possible. If carers can sit down and eat with residents it can make a huge difference to the mealtime experience.

MEALTIME ENVIRONMENT

- Appropriate and comfortable surroundings
 - Make sure the person can be seated in a good position for eating. Ensure that eating implements are easy to reach and use. Check that the temperature of the room is suitable – being too hot or too cold can be distracting.
- There can be a lot going on
 - Meals are busy times. Think about the environment and making as calm a mealtime atmosphere as possible.
 - For some, catching sight of other people's food or seeing or smelling the next course before they have finished the first one is confusing. Find out what works best for each person.
- Noise – try to keep it to a minimum
 - Pots, pans, crockery and cutlery make a lot of noise. This can help to cue the person in before the meal, but during the meal it can be disruptive.
 - Other background noise should be considered. Vacuum cleaners, washing machines etc should not be on during meals.
 - Quiet, soothing music has been shown to encourage people to stay seated for longer and eat more, but other TV or radio can be disturbing.
- Visual disturbance
 - Think about where the person is facing. Will their attention be drawn to what is going on outside the window or in the corridor? Are people walking about in their field of vision to serve the meal? Has a TV been left turned down but with the screen still on?
 - Do they manage better where they can see other people eating or when they are on their own?
 - Visual perception may be disturbed by hallucinations or just by failure to recognise food for what it is. If a person perceives a mushroom as a slug for example, allowances may need to be made.
 - Does the colour of the food stand out against the background of the plate? It is hard to see a poached egg or mashed potato on a white plate. Are different colours available if required?

- Clutter

- Studies show people with dementia do not always identify their own space at the table. There can be problems with people taking food which was served to somebody else. Square tables with a corner either side of each place seem to help. A plain table cloth also reduces confusion as patterns can look like objects which the person tries to pick up. Plates, cutlery and drinks stand out better against a plain background.
- For some people it is important only to put out what they need. If they just use a fork, for example, do not set the place with a knife and spoon as well as this may just cause confusion. Similarly, flowers and condiments may look nice, and can help create the right environment for some, but for others could be a distraction.



ORAL HYGIENE

Poor oral hygiene can be the cause of multiple problems. Effective regular oral hygiene is essential for safe and comfortable eating and drinking.

Good oral hygiene:

- Increases comfort in the mouth
- Helps taste and smell and increases the enjoyment of food
- Alerts carers to oral infections or soreness
- Alerts carers to food left behind in the mouth, which might be due to swallowing difficulties
- Reduces the risk of chest infections by preventing the build up of oral bacteria
- Can be therapeutic – for some

Remember:

- Make sure the teeth and mouth are cleaned two or three times a day with a toothbrush and toothpaste.
- If this is not accepted, a soft child's toothbrush and mild toothpaste may be tolerated better. Use of a "finger toothbrush" might be possible with some people (further information is available on the internet).
- Everyone requires oral care, even if they have no teeth !

A person with dementia may retain the ability to brush their teeth or mouth when they are not managing many other aspects of self-care. Always let the person have a go first.

POSTURE FOR MEALTIMES

Posture is very important in the swallowing process.

A complex series of movements closes the airway and pushes the mouthful of food or drink into the food-pipe. The timing and co-ordination of these movements is crucial, as breathing must not be interrupted for long, but particles of food or drink must not be allowed to enter the lungs.

Head and neck positioning affects the freedom of movement of the muscles.

If the neck is extended forwards this tightens the muscles and reduces the range of movement. It may also inhibit the initiation of the swallow.

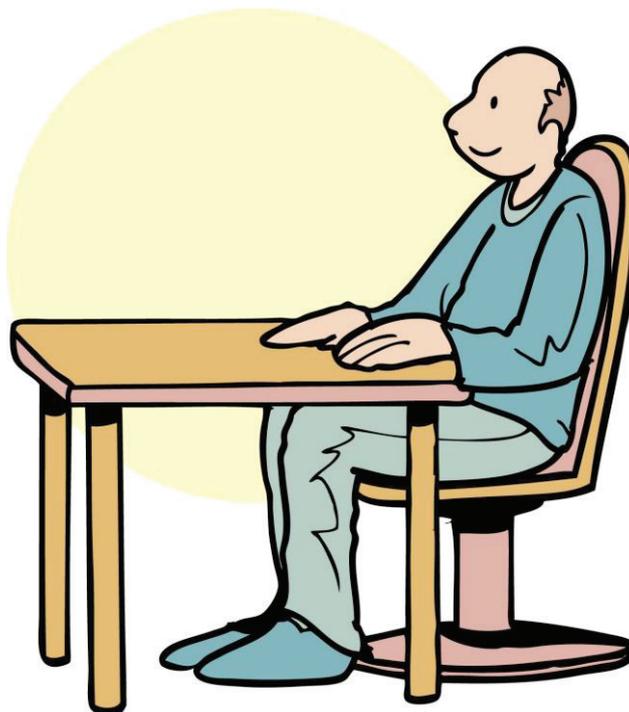
Movement is also restricted if the head is tilted back. A reclined posture also allows fluids to flow downwards into the throat, which may cause problems if the swallow is slow to trigger. Crumbs can also fall back into the airway in this position.

Sitting position also affects how well food travels down the food pipe into the stomach.

The optimum posture for swallowing is sitting in an upright chair, with a straight back and level chin, facing forwards.

This posture is not always possible, but it should be the benchmark for safe and effective swallowing.

If a person is sitting in a recliner chair, this should be put in an upright position before meals.



WHAT TO DO IF SOMEONE IS NOT EATING ENOUGH

Some additional simple steps can be taken to encourage a person to eat more.

- **Self feeding is best but needs support.** Statistics show people generally do better if they can feed themselves. Not only are they in control, but also the action of moving the hand to the mouth helps to prepare the swallow process. However, there comes a point when managing independently becomes difficult. Rather than taking over, it may be helpful to offer minimal support and encouragement – occasional guiding of the spoon or helping to load the fork for example. Adapted cutlery, plate guards and non-slip mats may help the person to manage on their own.
- **Finger-foods.** Some people find cutlery awkward but are quite happy picking food up in their fingers. Food can be served in this form.
- **Delivering food as medication.** One study showed that a very effective way of making sure people ate enough was to record snacks as though they were medication. Ensuring food intake is adequate can be as crucial to health as a medicine.
- **Smaller meals more often?** As mentioned earlier, some people do better eating little and often. This can be hard to manage in a care-home environment, but results can make it worthwhile.
- **Healthy eating is not always the top priority.** Concentrate on providing favourite foods if necessary. If a person eats nothing but chocolate and porridge, this is a lot better than not eating anything.
- **Food or drink left in the places where the person tends to wander.** Studies have shown this can be an effective way of boosting intake for some people, though this may not be feasible in some care settings.
- **Family mealtimes.** In settings where staff eat alongside residents, and at family mealtimes at home, people show less agitated behaviour and do not leave so much food uneaten. Quiet music can also help people to eat more.
- **Familiar mug/plate from home.** As mentioned earlier, this can be enough to orientate the person in an unfamiliar environment and help them settle down for a meal.

In some situations it may be necessary to refer to a dietitian, but before this, check that the above advice is being followed.

HELPING TO FEED

Feeding somebody is not as easy as it looks. Have you tried letting somebody feed you a whole meal? Have a go. Think about how it made you feel.

The following reminders may be helpful:

- **Not all or nothing**
 - A person may be able to feed themselves part of the meal. Encourage as much independence as possible as it helps the person feel in control, and helps the swallowing process.

- **Cramming**
 - If a person overfills their mouth, try cutting the food differently or using a smaller spoon or fork. If they keep adding food before they have chewed or swallowed, it may be necessary to put the next mouthful out of reach until they are ready. Verbal reminders to swallow and a gentle hand on the arm may also help.

- **Take time and don't convey rush**
 - If you seem to be in a hurry the person will be aware of this and may well not eat as much.
 - Stay with them and maintain a good level of eye contact. Avoid talking to other people as the person may be distracted by this.

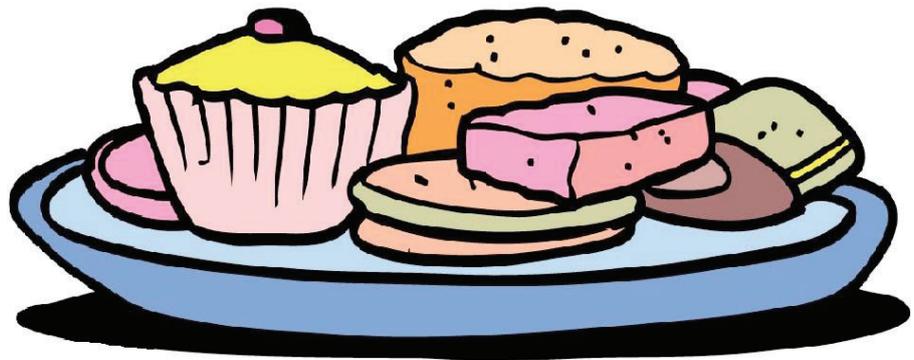
- **Remember positioning and consistencies**
 - Make sure you know what is best for the person.
 - Make sure you are comfortable as well as the person you are helping. Sit on a level with them so that your presence is not intimidating.

- **Consider Presentation**
 - Think about what would appeal to you. Would you eat the same meal?
 - Keep different flavours and textures separate.

- **Say what is in each mouthful**
 - Being able to anticipate the flavour is important.

- **Be aware of the senses**
 - Sensory stimulation can come from flavours, temperature, colour, pressure of spoon/fork and from what you say. Research shows that a variety of textures and colours is more appetizing.

- The swallow works best if all the senses are stimulated. Offer verbal prompts, including praise.
- **Watch for the swallow to happen**
 - Wait, and watch the neck to see the swallow movement.
 - Ensure the mouth is clear after the swallow.
- **If you are not a family member, imagine you are helping a loved one**
 - Be compassionate and caring when feeding.



COMPENSATING FOR PROBLEMS WITH EATING AND DRINKING

Many difficulties can be resolved by adjusting the person's posture or changing food consistencies. Specialist advice is not always needed. However, there are some important points to be aware of.

Head position

A wide or shallow cup which prevents the need to tip the head back for drinking often resolves coughing on drinks. Avoid spouted beakers if possible as most require the person to tip their head back significantly.

Using a straw is another way of enabling the person to keep their chin level, but straws should be used with caution:

- If somebody has a delayed or weak swallow, a straw could increase the risk of aspiration of liquid into the lungs, so it is important to be very aware of any signs of this.
- A straw should never be used to permit drinking in a reclined position if a better posture is possible.
- Not everybody is able to suck effectively through a straw.
- Valved straws can help a person with a weak suck.

Food Consistencies

If a person is finding it difficult to eat, it may be tempting to give purée to be on the safe side. This may be appropriate, but it is not always the best consistency. Some people swallow better if the food needs chewing, and soft finger foods or a soft, moist diet may be suitable. For many people, purée is less appetizing than the food they have been used to and means they eat less. Also, the nutritional content is lower because of the amount of liquid, so this needs to be allowed for.

Take care with mince. The bits can be difficult to deal with. If a soft diet is needed, mince should be in thick gravy so the bits do not separate. If a puréed diet is required, mince should be blended.

Thickening drinks

If a person's swallow is delayed, thickening powder may be prescribed to use in their drinks. This can slow the liquid down enough to prevent problems. Some people drink less if their drinks are thickened, so the benefits of thickener must be balanced against the risk of the person becoming dehydrated. Thickener has very little nutritional content.

Clear fluids, i.e. fluids with a very low protein or fat content, are less likely to cause infection than more nourishing drinks if they are breathed into the lungs.

ALTERNATIVES TO HIGH-RISK FOODS

When certain foods become difficult, they can sometimes be modified to be manageable. Here are some examples of high-risk foods with alternatives which are generally easier and safer to eat.

High-Risk Food	Alternative
Chewy meat	Slow cooked, finely chopped, in thick gravy
Crisps and nuts	Snacks made of puffed corn which melt in the mouth.
Grapes, apple	Banana, peach, pear, strawberry
Biscuits, fruit crumble	Soft sponge cake, dunked biscuits, add cream or custard to crumble.
Granary bread, other bread	Wholemeal is usually the easiest bread to manage. If all bread is difficult, try soaking in milk or soup stock.
Muesli	Wheat biscuit cereal, porridge
Lettuce, salad leaves	Broccoli or cauliflower, cooked and cooled.
Other salad	Beetroot, cooked and cooled, cubes of cooked carrot
Rice	Overcooked, with thick sauce
Toast	Crusts removed, lightly toasted, lots of spread.

SEEKING ADVICE

Everybody coughs on their food occasionally. If somebody is having **significant** problems with swallowing, medical advice should always be sought. Referral to speech and language therapy services for specialist assessment and advice may be indicated, discuss this with the GP.

The signs to watch for are:

Immediate signs:

- Coughing and choking
- Respiratory difficulty
- Change of colour
- Wet or gurgly voice
- Throat clearing
- Pocketing food in mouth
- Multiple swallows on each mouthful
- Perspiration on brow or watery eyes after swallow

Underlying signs:

- Recurring chest infections
- Avoiding/refusing food or drinks
- Respiratory problems
- Hunger
- Dehydration
- Weight loss
- Not coping with saliva/secretions

It may be helpful for you to keep a diary of coughing episodes which includes when, where and what was being eaten or drunk, and how it was given.

Good communication between everybody involved in a person's care is very important to ensure that problems are identified, care plans are up to date and advice is followed.

WHEN A PERSON CAN NO LONGER EAT OR DRINK RELIABLY

If a person does not have a safe swallow, or is not eating or drinking, it can be very distressing.

The following reminders may be helpful:

- Partnership with relatives and forward planning help prepare for difficult decisions.
- Not eating can be a natural part of the end of life for some people.
- It is important not to make any assumptions but continue to respond to the person's needs. The anxiety or distress of the carer should not affect judgement: it has been known for carers to withhold nourishment inappropriately because they were frightened the person might choke.
- It may be appropriate to continue careful oral feeding, in spite of an element of risk, in the interests of comfort. Sips or tastes should be offered but never forced.
- The person should not be fed in their sleep, nor forcibly woken to feed.
- Medication can be provided non-orally.
- Mouth care should always continue.
- **Take your cue from the person.**

Mealtime Memo

Make sure I am comfortable, in a good position and not in pain

Everybody is different, find out what I like

Appetising smells and presentation help me enjoy my food

Let me feed myself if possible, but help me if I need it

Tell me what I am eating and go at my pace

I like a calm environment without clutter, clatter and chatter

Modify the consistencies to suit me

Eat with me when you can

EATING AND DRINKING CARE-PLAN

Name:	Filled in by:	How this is achieved	Date:
	My likes and dislikes are known and followed		
	My mouth is clean		
	I know when a meal is about to happen		
	I am comfortable for meals, in a good position for eating and not in pain		
	Side effects of medication do not interfere with eating and drinking		
	My food is presented in an appetising way		
	I know what I'm eating		
	My eating utensils are easy to reach and use.		
	Appropriate textures are given		
	Suitable support with feeding is provided		
	There is no unnecessary noise or disturbance		
	Any signs of swallowing difficulty are communicated to senior staff or the GP		
	I am eating and drinking enough		

EATING AND DRINKING CARE-PLAN - example

Name: <i>Kim</i>	Filled in by: <i>wife</i>	Date: <i>01/01/12</i>
My likes and dislikes are known and followed		Kim's tastes have changed, but he stills hates cheese so I avoid it.
My mouth is clean		I make sure his mouth is cleaned thoroughly with a toothbrush morning and evening.
I know when a meal is about to happen		Before a meal I take Kim to the toilet and then we go through to the dining room. I encourage him to arrange the cutlery while I dish up.
I am comfortable for meals, in a good position for eating and not in pain		He has his pain killers a couple of hours before his main meal. He has a chair with a high back to I can support his head in the right position.
Side effects of medication do not interfere with eating and drinking		He seemed to be coughing a lot. I talked to the GP who has changed his medication and it is better now.
My food is presented in an appetising way		I try to make sure there is some colour and the food looks nice.
I know what I'm eating		I talk to Kim about what is on the menu, and about the smell and taste.
My eating utensils are easy to reach and use.		He has a special fork with an adapted handle.
Appropriate textures are given		He can't manage bits or skins so I avoid these.
Suitable support with feeding is provided		He manages if I am sitting with him. I make sure I have everything to hand because he gets anxious if I keep getting up and doesn't eat as much.
There is no unnecessary noise or disturbance		I've noticed the washing machine distracts him so I make sure I don't put a load on before a meal.
Any signs of swallowing difficulty are communicated to senior staff or the GP		Since I talked to the GP the coughing has been OK.
I am eating and drinking enough		Kim is weighed every month. He began losing weight but I've been giving him snacks in between meals and he had stayed the same the last time.

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Rebecca Kellett is a Specialist Speech and Language Therapist working with adults in the community of Dumfries and Galloway. She has a special interest in people with Dementia and how we can help people overcome barriers to participate fully in their environment. Rebecca has completed the NHS Dementia Champions course and continues to promote joint working between professionals, carers and people with dementia.

Contact: dumf-uhb.speechlangtherapy@nhs.net

FURTHER SOURCES

The following links provide a wealth of further information:

www.alzscot.org.uk

www.cwt.org.uk

www.scotland.gov.uk

www.scie.org/dementia

ILLUSTRATIONS

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