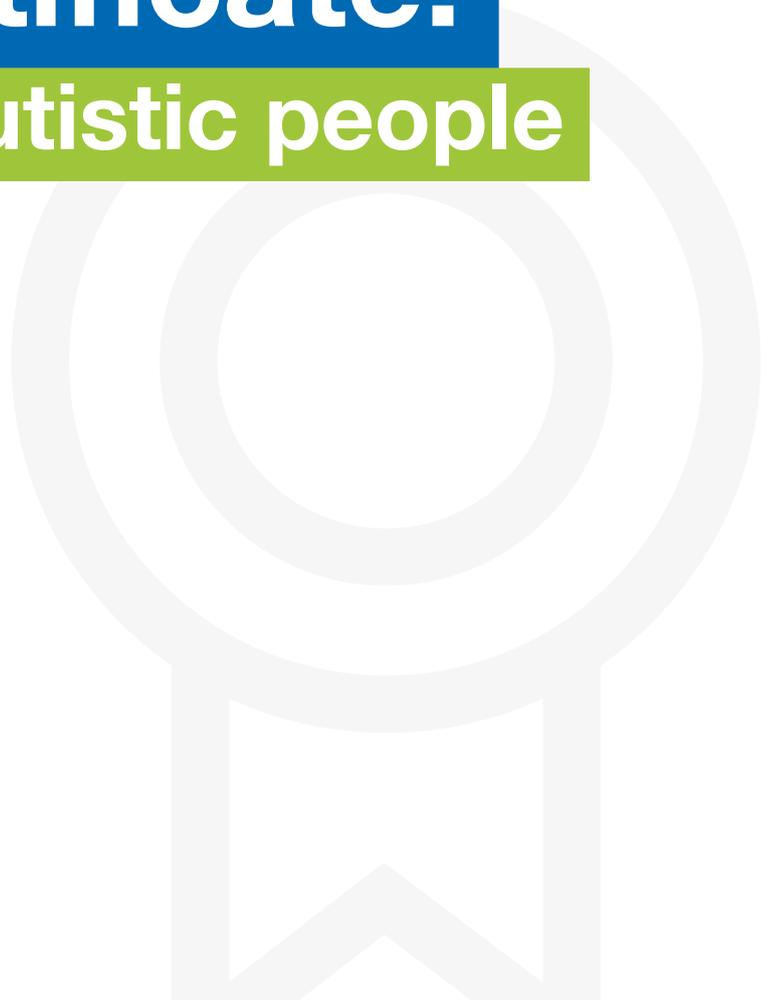


Tailoring the Care Certificate:

Supporting autistic people



Introduction

The Care Certificate was introduced in 2015 to ensure that all social care and healthcare workers have the knowledge, skills and behaviours to provide compassionate, safe and high-quality care and support.

Some of the standards have been contextualised to different working situations or services to help new workers, or workers new to a particular area of care, to apply the content to their specific roles.

The Care Certificate has been contextualised in six areas:

- autism
- dementia
- end of life care
- learning disability
- lone working
- mental health

This document includes the **autism** contextualised standards.

The resource can be used alongside other resources for example, 'Tailoring the Care Certificate: Services for people with a learning disability' when a worker is supporting people who are living with a learning disability and autism.

[Further Care Certificate resources can be found here.](#)

This resource doesn't cover all of the Care Certificate standards as not all need contextualising, some are universal and apply in the same way to all areas of work. For example 'Standard 12 Basic life support' applies in the same way to all areas of care.

This resource is **introductory level only** and designed to be used in **addition** to, and to **enhance**, current Care Certificate delivery and resources, such as the Care Certificate workbooks and presentations. Required additional learning and specialist skills should be based on: [The Core Capabilities Framework for Supporting Autistic People](#). This sets out the skills and knowledge that health and social care workers need to deliver high-quality care and support for people with autism. National trials are taking place with regards to Oliver McGowan Mandatory Training in Learning Disability and Autism. When these are complete in 2022 we'll review this resource in line with workforce induction requirements.

Who should use this resource?

'Tailoring the Care Certificate: Supporting autistic people' is designed to support workers new to this area and can be used by learners, Care Certificate trainers and assessors.

How should the resource be used?

'Tailoring the Care Certificate: Supporting autistic people' isn't a mandatory resource. It can be used in several ways, by a number of people, to enhance current Care Certificate learning and development. There are activities included throughout. These could be completed verbally or written down or adapted to be included within a trainer's or assessor's other resources.

The resource could be used:

- in group learning environments, face-to-face or virtually
- in one-to-one learning or supervision sessions, face-to-face or virtually
- as pre-reading for learners
- as part of assessment resources
- as part of staff supervisions.

Learners might use this resource:

- to refer to during their Care Certificate programme, refer back to after completion or to provide context to their other learning.

Care Certificate trainers might use this resource:

- as a handout in training sessions
- to stimulate discussion in group or one-to-one environments
- to review their current training package against.

Care Certificate assessors might use this resource:

- to stimulate discussion during assessment
- to aid in reviewing their assessment documentation.

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Standard 1: Understand your role

Autism affects people in different ways. Each person you work with will have their own individual support needs. Some autistic people have a learning disability and some don't.

There's a vast network of people and services available for autistic people to access. You'll need to be aware of an individual's support network, and understand your role within it, to promote independence and ensure the best outcomes.

These people and services may include:

- advocates and self-advocacy groups
- autism support groups
- day care/education provider
- employment teams
- family, loved ones and friends
- GP
- housing services
- mental health services
- neurologist
- occupational therapists
- other relevant healthcare workers
- social networks
- social worker
- speech and language therapist

The different services, roles and responsibilities may be confusing for the person you are supporting. Part of your role will be to help the person understand how different services can support them.

You'll need to communicate clearly, professionally and focus on building successful relationships with the person and those involved in their care and support. Follow agreed ways of working when sharing information with these partners, which may include recording and reporting.

Advocacy

Advocacy services are used across all social care services and can support autistic people to ensure they have their voices heard.

Example:

Sally has lived at the supported living service where you work for the past six months. During this time, care workers have struggled to engage Sally in conversations about her care and support plan. You talk to Sally and those supporting her about this. Sally says she'd like to be more involved but isn't sure how to be. Together, you agree ways in which Sally could be more involved and feel more confident and comfortable in contributing to her care plan. You all agree to:

- use visual aids and pictures to demonstrate what a care and support plan is
- focus on one or two sections at a time
- give Sally plenty of time to ask questions so she can make informed decisions
- involve people in discussions whom Sally feels are important to her
- help Sally organise and facilitate some of these meetings.

As you start to implement these changes together, Sally tells you she feels more involved and in control of her care and support.

This is an example of an effective working relationship between you, Sally and others she has chosen to be involved in her support.

Discussion point:

To help maintain independence in personal care, Sam needs some adjustments to the environment of his bathroom. Currently it's too overstimulating and his senses are overwhelmed. During a care and support plan review, Sam shares with the social worker the difficulties he is experiencing. The social worker agrees to make a referral for an assessment with the occupational therapist. Following this, the required adaptations are agreed and carried out in Sam's bathroom.

This is an example where there might be different types of partnerships involved in a person's life. As Sam's support worker consider:

- What different types of support do you think Sam may have needed throughout the process?
- What support may Sam need if there are any problems during the process, such as a delay with the adaptations?

Additional learning and resources:

- [Autism](#)
- [Core Capabilities framework for supporting autistic people](#)

Standard 3: Duty of care

Duty of care describes your obligations towards the people you support in your role as a social care worker.

Duty of care and the Mental Capacity Act 2005 (MCA)

There are five main principles that shape the MCA and these are:

1. Assume a person has capacity unless proved otherwise.
2. Do not treat people as incapable of making a decision unless all practicable steps have been tried to help them.
3. A person should not be treated as incapable of making a decision just because their decision may seem unwise.
4. Always do things or take decisions for people without capacity in their best interest.
5. Before doing something to someone or making a decision on their behalf, consider whether the outcome could be achieved in a less restrictive way.

These principles will always help guide your duty of care.

To ensure the person you're supporting has the correct information to make as many informed decisions about their life as possible, you'll need to consider:

- communication style
- any support and encouragement they may need
- the time they need to process and make informed choices.

Sometimes there can be dilemmas between a person's choice and your responsibility as a care worker. If the person has mental capacity, they have a right to take risks and make decisions that some people may consider unwise but you must always try to find ways of working with the person to minimise any risks as much as possible. You can help the person understand the potential consequences of their actions and possible safer alternatives. If the risk remains too high you should refer to your organisation's safeguarding policies.

Example:

Over the past few days, Lubna appears to have been neglecting her personal hygiene. Others in the service are starting to comment on this. Lubna says that it's her choice not to maintain her personal hygiene.

Lubna has been assessed as having the mental capacity to make her own decisions.

As part of your duty of care you could support Lubna in the following ways:

- communicate clearly and sensitively about the situation
- consider ways you may have to adapt communication methods, giving time and space to Lubna
- listen to how she is feeling and to any concerns or problems she may have
- try to establish if there are any underlying factors which may be contributing to this, such as anxiety, sensory issues within the environment, her mental health, well-being or current routine and support
- discuss the potential risks and impact of not maintaining her personal hygiene
- ask Lubna what support (if any) she would like with her personal care
- agree any changes needed with support in this area which will then be updated in her care and support plan.

A person's mental capacity can change and each individual and situation will require different types of support. Always use the support available in your workplace to help resolve dilemmas and difficult situations you may face when providing care and support.

In your role there may also be times when there is confrontation. Some factors that may cause confrontation with an autistic person you're supporting may include:

- biological such as pain, hunger, tiredness or illness
- social such as boredom or disengagement
- environmental such as loud noise, temperature, smells or busy environments which could cause sensory overload
- psychological such as trauma, feeling lonely, not having decisions respected or being misunderstood
- distressed behaviour
- an unmet need.

Always remember that an individual's behaviour is a form of communication. It's important to respond in an accepting and positive way and to follow any strategies as provided in the individual's care and support plan. Seek advice and support from your manager and colleagues if needed.

Activity:

Jona lives with four other people in a supported living service with a communal kitchen. Jona keeps taking other people's food from the fridge.

- Why might this cause a confrontation with other people living in the service?
- What risks could this situation present?
- What support could you provide to Jona to understand the consequences of his actions?
- How could you reduce the potential for confrontation?



Additional learning and resources:

- [Autism and mental capacity law](#)
- [Mental capacity](#)

Standard 4: Equality and diversity

Discrimination against a person occurs when a person or organisation treats that individual unfairly because of their disability and/or any other protected characteristic they have such as their marital status, race, gender or sexual orientation. Some autistic people don't consider autism to be a disability, others do. People can experience double (or multiple) discrimination. Discrimination is often obvious and direct, but it can also be subtle and indirect.

Example:

Direct discrimination: a person is told they can't complete a training course as it isn't suitable for an autistic person.

Indirect discrimination: a person starts a training course and the training provider refuses to send course handouts in coloured and large font as they don't normally do this.

Discussion points:

- What legislation is in place to protect autistic people from discrimination?
- What protected characteristics?
- What local support networks are available to help promote equality and diversity?

Society is developing more of an understanding of autism. This is gradually leading to a more compassionate and person-centred approach to care and support, with campaigns raising the public's understanding, such as the Hidden Disabilities Sunflower campaign and Oliver's campaign:

Hidden Disabilities Sunflower campaign

Wearing the Hidden Disabilities Sunflower discreetly indicates to people around the wearer, including staff, colleagues and health professionals, that they need additional support, help or a little more time.

[Find out more](#)

Oliver's campaign

This is a campaign for better health care for people who have a learning disability and/or are autistic.

[Find out more](#)

The plan for Oliver McGowan Mandatory Training in Learning Disability and Autism will help ensure that people with a learning disability and autistic people will have a more positive experience of health and care services.

Despite these campaigns, autistic people still face stigma and discrimination and autistic people can be at higher risk of mental health problems. One of the challenges to positively supporting an autistic person is that autism is invisible and affects individuals in different ways which people don't always recognise.

Example:

Natasha is autistic and has shared some of her own experiences and challenges in relation to equality and diversity:

- when Natasha tells people she is autistic, they often begin to talk down to her
- when Natasha asks for help, she is often challenged because people can't see she has autism
- Natasha can't always access the support she needs at the right time
- Natasha finds there is lack of help and support when using health services especially when going into hospital
- the use of public transport brings many challenges for Natasha due to accessibility and how others respond to her when in the community.

You need to recognise when someone you're supporting is being discriminated against and know how to challenge discrimination. You need to remember that the person you're supporting may or may not want you to challenge it, may want to challenge it themselves or be offered access to an independent organisation which can help them.

Supporting an autistic person means enabling them to have access to services and activities they want. They may need things done in a different way to enable them to have equal opportunities.

Discussion point:

Working in an inclusive way and accessing information, advice to support an individual's diversity, equality and inclusion.

Everton is currently living with his parents and is planning to move into his own first home.

- What different types of support may Everton need access to?
- How could you support Everton to access the help and guidance he needs?

Standard 5: Work in a person-centred way

Autism affects the way a person relates to and makes sense of the world around them. To understand and provide person-centred care, you should:

- understand that every autistic person has a different combination of traits and sensitivities and is unique
- recognise the importance of seeing each person as an individual
- recognise the person's unique abilities and capabilities
- understand the person's own experience of autism
- avoid making assumptions
- ensure the person's care and support plan is kept up-to-date
- support the person to make plans for their future
- support positive risk taking.

Autistic people may experience sensory differences (over- or under-sensitivity) with:

- light
- touch
- sounds
- tastes
- smells
- colours/patterns
- temperature

The differences experienced can cause or increase anxiety which may lead to the person being distressed. The person may avoid or leave certain environments or situations due to the differences they experience.

Discussion point:

Carlos enjoys walking and follows a specific route around the local area. One day his carers decide to drive Carlos to a different location for a change of scene. When they arrive, Carlos doesn't want to leave the vehicle.

- Why might Carlos find going for a walk in a new location difficult?
- What should his carers have done differently?

Understanding how sensory differences can impact on an autistic person will enable you to know when you should make any environmental adjustments.

As you get to know the person you are supporting, you may be able to recognise changes in their behaviour. This could be the person trying to communicate a need, such as a physical or emotional need, or the sign of a health problem which may cause discomfort or pain.

You'll need to take the appropriate action, which will always include actively involving the person regardless of their ability to communicate verbally with you and following agreed ways of working for recording and reporting any changes.

Tailoring the support you provide so that it meets the specific needs, wishes and preferences of the person being supported is essential when providing a social care service and is likely to have a positive effect on a person's wellbeing and their sense of identity.

Example:

James and Holly are siblings, and both have autism. They live together in a shared lives scheme.

James finds communication and interaction with others very difficult. He rarely speaks and likes to spend time alone in his room when at home. James likes predictability. He attends college independently three mornings a week and he excels in his coursework.

Holly likes to be close to people and gain reassurance from them about what is about to happen next. Without this level of reassurance, she can quickly feel frightened and confused. Holly requires support in all aspects of her daily life and when going out.

Even though James and Holly live together, the support they need and receive is very different. They have individual care and support plans, personal goals and receive support at different times of the day.

Identity

Our identity is what makes us unique and is our sense of who we are. It encompasses personality, spirituality, sexuality, values and culture and is built from our beliefs and experiences.

Finding and understanding your identity can take time and experimentation – often, but not always, through adolescence and early adulthood - and people’s identity can change over time.

Exploring and understanding our own identity can lead to periods of confusion and anxiety. These feelings may be heightened for some autistic people. But exploring identity can also be life-affirming and elating. It’s important to support an autistic person to feel safe to explore and develop their own identity as it’s so closely linked to self-esteem and self-worth.

Additional learning and resources:

- [Improving Access to Social Care for Adults](#)
- [An independent guide to quality care for autistic people](#)

Standard 6: Communication

Autism is a lifelong developmental disability and will usually affect a person's communication and social skills.

Communicating with the person accessing care is an essential part of providing person-centred care. It's important to understand that autism is different for each person and the way each person communicates will be different. Various situations and circumstances, such as a change of environment or routine, can also trigger a change in the person's communications needs.

Autism can present barriers for the person in being able to communicate, such as:

- understanding and using non-verbal communication such as body language, facial expressions, eye contact and touch
- understanding social cues
- feeling overloaded with information and stimulus which can lead to the person 'shutting down', showing distressed behaviour or simply agreeing
- accepting change and different routines
- rigidity in thinking (the impact this may have on communication)
- ability to form and maintain relationships
- overload of too much information without enough time to process it
- other conditions which can also impact a person's communication needs such as a sensory impairment, learning disability, mental health problems, dyslexia and dyspraxia
- the person hearing at a louder or quieter volume than you expect (hypersensitivity/hyposensitivity to noise) and/or not being able to filter out what is important.

When communicating with an autistic person, you may need to use different techniques to ensure you both fully understand each other, such as:

- using the person's preferred communication method
- knowing whether they prefer closed questions, such as "where are you feeling pain?" or open questions such as "how are you feeling today?"
- providing factual responses with the right amount of detail for the person, such as "we're going shopping at 1pm", instead of "we're going later"
- creating the right environment with minimal distractions and considering all sensory needs of the person
- gaining the individual's attention, eye contact might be uncomfortable or might mean the person is not paying attention, so you need to agree how the person can let you know you have their attention

- observing the person’s body language for responses and reactions (sometimes the person may not want to communicate verbally)
- being aware of difficulties and differences in non-verbal communications such as use of facial expressions and personal distance
- giving extra time for the person to process information and give a response
- not interrupting the person too soon or re-asking the question straight away
- avoiding ambiguous language and metaphors, such as “hang on a minute”, “watch the road” or “it’s raining cats and dogs” as an autistic person may take things literally or find this distracting
- using communication passports when the person is receiving care in a different environment
- using plain English and direct language in written communications and providing information in easy read format if the person requests this
- respecting the fact that they may like to hold sensory items to help keep them calm and focussed when communicating with others.

Various communication aids and technologies are also available to support autistic people. Other professionals, such as a speech and language therapist and support groups, can help with communication aids and technologies. The use of aids and technologies should suit the needs and preferences of the individual accessing care and support. Routine and predictability may be important and use of aids can really help to support communication. Some examples include:

- signs/symbols
- computers or tablets and other touch-screen, voice-generating devices
- pictures/photographs
- objects of reference
- easy read systems
- Picture Exchange Communication System (PECS)
- sequence boards which display steps of an activity
- calendar countdowns
- social stories and comic strip conversations.

An **object of reference** is something which can signify to the individual the next step, an activity or choice. Objects of reference should be relevant to the individual, and different people may use different objects of reference to signify the same activity. For instance, for one person, reference for going outside might be house keys whereas someone else’s reference might be their coat.

[Social stories](#) are used to help a person to prepare for a situation or event.

Autism-friendly environments

Everyday environments can be distracting and may impact the individual's ability to communicate. The use of autism-friendly environments can help to improve an individual's ability to communicate effectively.

[Find out more.](#)

Activity:

Ronnie has an upcoming dental appointment for some treatment which he has agreed to.

- Why might this situation change Ronnie's communication needs?
- How could you and others adapt the communication support provided to Ronnie leading up to and during the dental appointment?



Additional learning and resources:

- [Communication](#)

Standard 7: Privacy and dignity

In addition to the list provided in 7.2b of the Care Certificate, promoting someone's privacy and dignity could also include understanding, and respecting the person's:

- own personal space and giving them space when they want or need it
- personal information
- lifestyle choices
- sexuality and/or gender
- rights and choice to have personal relationships, including intimate and sexual relationships
- rights and choice to have independent social relationships, including meeting friends and family
- need to carry out specific routines, if these are interrupted, this could lead to behaviours which could compromise the individual's dignity.

As already explored in [Standard 6](#), autistic people may also face barriers with their communication needs, such as difficulties in understanding social cues and subtle aspects of non-verbal communication. This may lead to the person:

- not being able to explain verbally that they need privacy
- not being aware of others' need for privacy
- finding it difficult to respond appropriately in a situation
- finding it difficult to remove themselves from a situation
- finding it difficult to know when and how to ask for help
- not understanding and/or not being able to demonstrate socially appropriate behaviour in certain situations
- needing help or support to keep safe in situations where there may be risk.

You will need to consider how you can recognise when someone wants or needs support in a situation or has a need for privacy and then support the person in the way that is right for them.

Dignity and independence

A key part of promoting someone's dignity is enabling the person to make their own choices and to be as independent as possible.

Different situations can be overwhelming for the person and you will need to ensure a person's dignity and independence is always upheld.

Example:

Lucia has requested a visit to the GP and has asked for your support in attending the appointment. Last time Lucia visited the GP, she told you she felt the GP didn't listen to her and she felt confused by the advice she was given.

To improve this situation, you could:

- support Lucia to prepare for the appointment by writing down what she would like to discuss
- ask Lucia in advance how you can support communication with the GP
- encourage communication between the GP and Lucia, and check if Lucia understands
- ask the GP to provide information in a format Lucia understands
- check if Lucia is satisfied with the outcome of the appointment.

Choices and active participation

Every person is different, and autism affects people in different ways. Each person you support will have unique abilities and capabilities.

You should actively encourage the people you're supporting to participate in their care and support to enable them to maintain as much independence and dignity as possible. This includes making choices and acknowledging a person may need additional support in this.

To support someone to make their own, informed, choices you could provide:

- a clear and structured approach to informed choice, there may be several elements of a choice the person needs to make
- up-to-date information which is in a format they can understand
- information about any risks and how the person can minimise this
- additional time as needed to support decision making, allowing time also for the person to process information.

Activity: Support individuals to make informed choices and support the active participation of individuals



Evan is about to start receiving a new domiciliary care package. Evan has been funded six hours a week for support with going out in the community. You've been asked to help develop Evan's support plan with him and he needs to decide how and when he'd like to make use of this support.

How could you support Evan to ensure he has an informed choice in how he uses his support hours?

You should be aware of how your own personal views or experiences could influence or restrict the choices of the person you are supporting or affect their ability to actively participate in decision-making. Sometimes, others' personal views could influence or restrict the choices of the person you're supporting, for example someone involved in the person's life may feel it's too risky for them to travel alone.

Standard 8: Fluids and nutrition

Maintaining fluids and nutrition

You could play a key role in supporting the person to choose and prepare balanced meals.

As already explored in [Standard 5](#), many autistic people experience sensory differences which can affect tastes, smells and textures. This can impact on the person's ability to manage their fluids and nutrition and their experiences of eating and drinking. Sensory differences could affect each person differently in different situations, and may include the person:

- choosing foods which are predictable and the same
- having specific preferences with how food is prepared and presented
- being reluctant to try new foods
- having specific routines associated with eating, drinking or mealtimes
- displaying ritualistic behaviours around eating, drinking and mealtimes
- demonstrating anxiety around food and drink.

The person may also experience sensory differences with the social and environmental aspects of eating and drinking and these also need to be considered.

Example:

Jenny prefers to eat white-coloured food which includes white bread, white rice, white chocolate and white cheese. This helps Jenny to feel safe as the food is predictable and looks and tastes as expected.

Jenny has expressed that she would like to visit a restaurant for a meal but is feeling anxious about the food on offer and if there'll be anything she can choose from.

You discuss this with Jenny and find out how she would like you to support her. This includes:

- finding a restaurant which serves a portion of white rice alone and supporting Jenny to go there and eat that
- supporting Jenny to discover and try other white foods without pressure and in a situation where she feels calm
- establishing Jenny's preferences with tastes and textures
- exploring other foods which are nearly white in colour
- looking at menus of restaurants
- when Jenny is ready to try other foods in a restaurant, choosing a suitable restaurant environment, where there won't be added sensory issues affecting her.

Autistic people may have additional support and dietary needs which affect their ability to eat and drink well or increase the level of support they need. There might also be additional health conditions, food intolerances or the person may have an eating disorder. Low muscle tone and physical disabilities can also impact a person's ability to manage their fluids and nutrition. Some autistic people have lower interoception meaning messages from their body indicating hunger, fullness or thirst (as well as pain, tiredness, temperature etc) don't reach their brain or can't be interpreted correctly.

It's important that you follow the care and support plan of the person you're supporting and report any changes you notice. Also, that you support the person to make sure their care and support plan reflects their own choices and preferences.

Promoting and supporting good nutrition and hydration can take time with autistic people.

Other specialist workers and professionals may be involved, and you must ensure that you respect the choices of the individual concerned and support them to adhere to any professional advice which will be included in the person's care plan.

Discussion point:

Alex really enjoys his food and insists on having two large platefuls at every mealtime. Some workers will ask Alex to wait until others have finished before he can have a second plate and other workers will try to encourage Alex to understand that one plate is enough. Alex often appears anxious at mealtimes.

- Why could this situation be making Alex feel anxious?
- How might you support Alex to feel safe during mealtimes?
- How could you, the team and other professionals help Alex decide if he needs any support with healthy eating?

Additional learning and resources:

- [Eating](#)

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