

Supporting adult carers overview

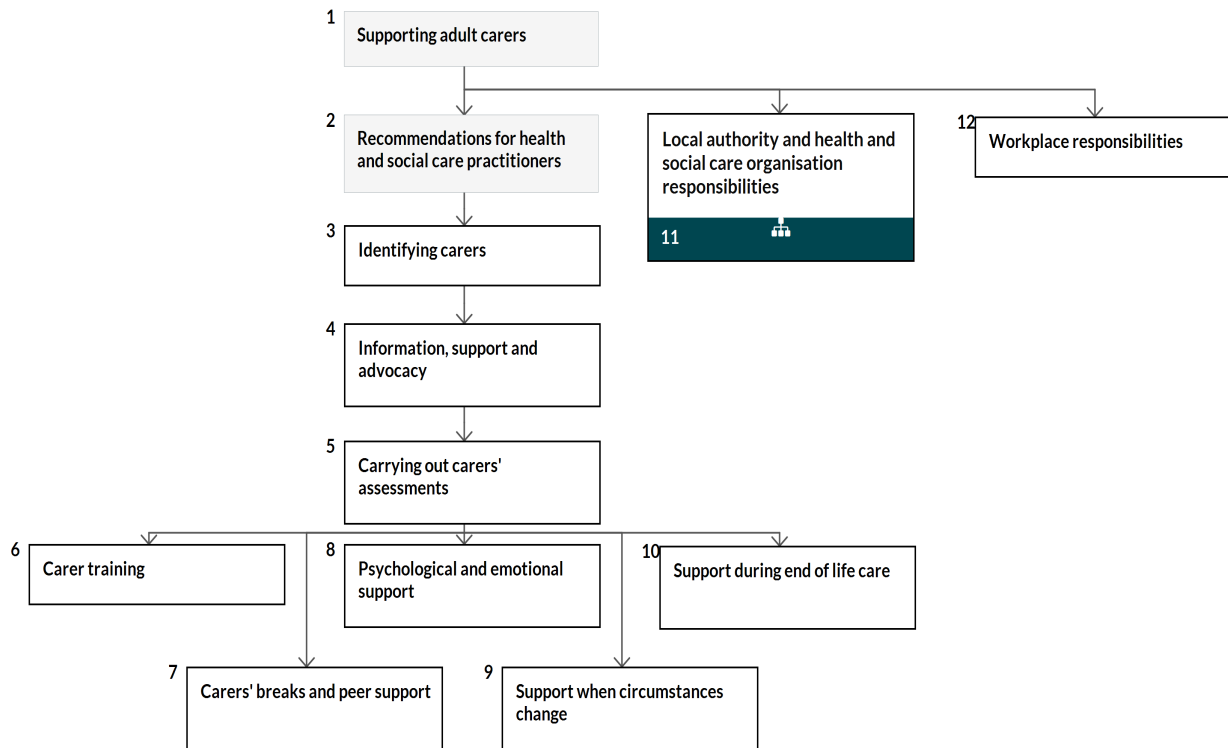
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

<http://pathways.nice.org.uk/pathways/supporting-adult-carers>

NICE Pathway last updated: 21 January 2020

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



1 Supporting adult carers

No additional information

2 Recommendations for health and social care practitioners

No additional information

3 Identifying carers

Recommendations for health and social care practitioners

Actively seek to identify carers (in line with the requirements of the [Care Act 2014](#)) and ensure that they know:

- about their right to a [carer's assessment](#) [See page 18], what this is and the benefits of having one
- how to obtain a carer's assessment
- that some support may be means tested
- that they can still access community support without formal assessment.

Use every opportunity to identify carers, including GP appointments, flu jab appointments, home visits, outpatient appointments, social care and other needs assessments, including admission and discharge assessments and planning meetings. Record details about carers you have identified (with the carer's consent).

Take into account that carers themselves may not ask for support from certain professionals, for example GPs, because they may not view support for carers as being part of that professional's role.

When identifying carers, be aware that some people may not view themselves as a carer because:

- becoming a carer can be a gradual process, and carers may not recognise the changing nature of their relationship with the person they support
- carers may prefer to continue identifying primarily as a husband, wife, partner, sibling, parent, child or friend rather than as a carer
- carers often become engulfed by competing demands, including working and caring, and as

- a result may overlook their own needs as a carer and may not seek support
- the person being supported may not accept that they have care and support needs
- the carer does not live with the person or the person has moved away from home, for example into supported living or residential care.

Encourage carers to recognise their caring role and seek support, explaining the benefits for both them and the person they care for, including:

- the carer's role and contribution can be acknowledged and their support needs addressed **and**
- carers can share valuable knowledge about the person they care for, which helps practitioners provide the right care and support.

Ask people with care and support needs whether anyone gives them help or support, apart from paid practitioners. Avoid making assumptions about who might be providing their care. Take into account that:

- other people offering help or support may not be family members or may not live with the person
- there may be more than 1 person involved in caring.

Practitioners involved in transferring people to and from hospital should seek to identify carers and refer them to appropriate services. Follow recommendations on:

- [support for family and carers throughout admission in the NICE Pathway on transition between community or care home and inpatient mental health settings](#) and
- [hospital discharge in the NICE Pathway on transition between inpatient hospital settings and community or care home settings for adults with social care needs](#).

Offer carers the opportunity to have confidential conversations about their own needs as carers separately from the person they are supporting.

If a person who has care and support needs is also identified as having caring responsibilities, their care and support needs assessment should take account of this. They should also be offered a carer's assessment to identify their needs as a carer. Assessments must meet the requirements of the Care Act 2014.

Ensure that carers who don't want or need a statutory carer's assessment are still offered information about how to access support.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

4 Information, support and advocacy

The right to information and support

Practitioners in health and social care (including healthcare professionals in primary and secondary care, social care practitioners, care and support workers and personal assistants) should use every opportunity to tell carers they have a right to information and support and how to get it.

See the NICE guideline to find out [why we made this recommendation and how it might affect practice](#).

Sharing information with carers

Discuss information with carers as well as giving them written materials. When providing information:

- ensure it is plainly worded, clearly presented and free of jargon
- be aware that smaller, more manageable chunks of information are easier to remember, and that visual aids or pictures can be useful
- encourage the carer to ask questions
- ensure that information is consistent.

Make information available in a range of formats to meet carers' needs and preferences, for example written leaflets, links to online and digital resources (including local and national websites and forums and social media) and information in accessible formats or different languages. For more about accessible communication see [NHS England's Accessible Information Standard](#).

Take into account that carers' information needs will change over time and whenever their circumstances or caring role change. Provide information and advice that addresses the carer's individual needs at the time when they need it and that helps them plan and prepare.

Offer to revisit discussions or provide the same information several times if needed, for example if there is a lot of complicated information to digest or the carer is experiencing emotional stress.

Practitioners responsible for providing and discussing information with carers should have the knowledge, time and communication skills to do so.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

Working with and involving carers

Health and social care organisations should promote ways of working with carers that acknowledge them as expert partners in care and value their skills and knowledge about the person they care for. These approaches should be incorporated into formal policies and processes.

Health and social care practitioners should work in partnership with carers and treat them as a valued member of the care team around the person being cared for, with the person's consent. This should include involving carers in decision making and care planning and keeping them up to date.

During discussions with carers about the person they are caring for:

- take into account the mental capacity of the person being cared for and their wishes around confidentiality (see [the NICE Pathway on decision-making and mental capacity](#))
- share with carers the information they need to provide care effectively and safely while respecting confidentiality (explain to them the constraints of confidentiality).

Be open and honest with carers about the health condition, disability or needs of the person they care for (with the person's consent), including when information is difficult or upsetting. Explain how it is likely to progress so that carers understand how their caring role might change in the future.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

Advocacy

If carers choose to have an advocate or representative to support them, health and social care practitioners should recognise this person's contribution and include them in discussions.

See the NICE guideline to find out [why we made this recommendation and how it might affect practice](#).

5 Carrying out carers' assessments

Carers' assessments

Practitioners from health and social care carrying out or contributing to [carers' assessments](#) [See page 18] should work together to ensure that:

- the assessment covers all relevant aspects of health, wellbeing and social care needs **and**
- details of the assessment are shared with other practitioners and organisations who are involved in the assessment.

The carer's assessment should be jointly produced with the carer and reflect what matters most to the carer and what might help them achieve this.

Be aware that a well-conducted carer's assessment may in itself be a therapeutic intervention or a means of preventing future problems.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

Preparing for and carrying out a carer's assessment

Arrange the timing of the carer's assessment according to the carer's preferences and the urgency of their need for support. For example, take into account:

- whether the person they care for is near the end of life
- the level of stress the carer is experiencing
- the timing of hospital discharge
- changes to the caring role
- any negative impact of delays on the health and wellbeing of the carer.

Provide flexibility in how, when and where carers' assessments are carried out, taking into account individual preferences and accommodating their caring responsibilities, working patterns and other circumstances.

Ensure that the assessment process is accessible, easy to navigate and complete, and tailored to individual needs, with information provided in a format that carers can understand.

Before a carer's assessment takes place, share information with the carer that helps them prepare.

Discuss caring in the context of the carer's own family and support networks, for example whether they share caring responsibilities with other people and whether they care for more than 1 person.

Discuss with carers the option to combine or link their assessment with the assessment of the person they care for, if they both choose to do this.

Do not make assumptions about the willingness and the ability of carers to carry out caring tasks when completing assessments for the carer or the person they care for.

If a carer's needs have been identified during a hospital-based assessment:

- inform the local authority (and/or any delegated care organisation) that a carer's needs have been identified
- ensure an effective process is in place to link the hospital-based carer's assessment with the community-based statutory assessment, to avoid duplication and so that meaningful support for carers is provided during transfer from hospital (including during a crisis).

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

Discuss replacement care

Ensure that [replacement care](#) [See page 19] is discussed as part of carers' assessments, including planning for any emergency replacement care that might be needed, for example if the carer becomes suddenly unwell.

See the NICE guideline to find out [why we made this recommendation and how it might affect practice](#).

Discuss education, training and employment

Discuss education, training and employment with carers during their carer's assessment. Explore the options and the support they need to remain in, start or return to work, training or education. This could include providing replacement care at home.

Ensure that practitioners carrying out carers' assessments have the necessary skills, knowledge and understanding of potential opportunities for returning to, or remaining in work, education and training.

Give carers tailored information about community services and support that could help them

remain in, start or return to work.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

Practitioners should encourage carers to discuss supportive working arrangements with their employers, including adjustments to make caring possible. Examples might include flexible hours, fixed hours or shifts, carers' leave, permission to use a mobile phone, technology to allow flexible working, or providing a private space to take personal phone calls. See the NICE guideline to find out [why we made this recommendation and how it might affect practice](#).

Outcomes and actions

Ensure there are clearly identified outcomes for the carer after their assessment.

After an assessment:

- ensure the carer understands the actions that have been agreed and what the next steps will be **and**
- share information (as appropriate) with other practitioners and organisations involved with the carer and the person they care for.

If a [carer support plan](#) [See page 18] is developed as a result of a carer's assessment, ensure it is monitored and reviewed regularly.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

6 Carer training

Offer training to enable carers to provide care safely. Training could include structured programmes or one-to-one guidance from a practitioner.

Involve carers in the design and delivery of carer training to ensure it covers skills and expertise relevant to them.

Offer carer training programmes that are:

- designed to improve carers' knowledge and coping skills
- accessible and available in a variety of formats, including printed or online materials or face

- to face
- tailored to the needs of carers
- delivered by practitioners with relevant knowledge and skills.

Training programmes for carers should include the following components, as relevant:

- general education about the health condition, disability or needs of the person they care for
- skills training to help them provide care, including how to understand and respond to changes in mood and behaviour
- principles of self-care
- training in communication skills to improve interactions with the person they care for
- advice on planning enjoyable and meaningful activities with the person they care for
- information about relevant services and how to access them
- future planning, including preparing for transitions.

Consider including the following in carer training programmes, as relevant:

- managing medicines
- managing diet and nutrition
- maintaining personal hygiene
- managing behaviour that challenges
- use of digital and assistive technology
- specific information that carers need to enable them to remain safe in their caring role.

Ensure that training programmes for carers are inclusive and address the needs and preferences of diverse groups, such as lesbian, gay, bisexual and transgender carers, and carers from diverse ethnic, religious and cultural backgrounds.

Training programmes for carers should provide a balance between learning, enjoyment, a chance to meet other carers and opportunities for [peer support](#) [See page 18].

Encourage carers to keep in touch with each other after they have attended a training programme and suggest ways they could do this.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

Use of equipment and adaptations, and moving and handling

Health and social care practitioners should involve carers during assessments for equipment and adaptations.

Health and social care practitioners should ensure carers have access to advice, guidance and training about appropriate use of equipment and adaptations, and safe moving and handling techniques.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

7 Carers' breaks and peer support

Carers' breaks

Health and social care practitioners should regularly discuss with carers the value of having a break from their caring role and explain the options available.

[Carers' breaks \[See page 18\]](#) should

- meet carers' needs for a break, for example in duration, timing, frequency and type of break
- be arranged in a way that provides reliable and consistent support to the carer (such as avoiding last-minute changes that could lead to additional stress for the carer).

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

Peer support

Tell carers about [peer support \[See page 18\]](#) and how to access it locally. Explain that peer support can help reduce a sense of isolation, provide empathy and social and emotional support, and enable them to share information.

See the NICE guideline to find out [why we made this recommendation and how it might affect practice](#).

8 Psychological and emotional support

Psychosocial and psychoeducational support

Consider providing carers with psychosocial and psychoeducational support, which should include:

- developing personalised strategies and building carer skills
- advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing
- information about emotional support services and psychological therapies for carers and how to access them.

Ensure that the range of psychosocial and psychoeducational support offered to carers includes group-based options.

Recognise that psychosocial and psychoeducational support may be needed at different stages of the caring experience and ask carers regularly whether they feel they would benefit from it.

Arrange the timing of psychosocial or psychoeducational support to suit carers' circumstances, taking into account other commitments such as work or other caring and family responsibilities.

When providing psychosocial or psychoeducational support to carers, take into account:

- the carer's preferred location
- whether they need support to attend (for example a practitioner to go with them)
- physical accessibility (such as help needed with transport)
- if [replacement care](#) [See page 19] is needed
- the carer's preferred format
- the cultural appropriateness of the intervention
- what follow-up will be needed.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

Psychotherapy and counselling

If a carer has an identified mental health problem, consider:

- psychotherapy and counselling interventions in line with existing NICE guidance **or**

- referral to a GP or mental health professional who can provide interventions in line with existing NICE guidance.

See the NICE guideline to find out [why we made this recommendation and how it might affect practice](#).

9 Support when circumstances change

Be aware that caring responsibilities may not end when the person being cared for moves away from home, for example into a residential care home.

Provide information and emotional and practical support to help carers prepare for and adjust to changes in their role, for example if the person they care for:

- becomes an adult
- makes the transition to adult services (see [the NICE Pathway on transition from children's to adults' services](#))
- moves away from home
- has a significant change in their health
- becomes terminally ill or needs end of life care (for recommendations on care near the end of life see [the NICE Pathway on caring for an adult at the end of life](#)).
- dies unexpectedly.

Provide information and emotional and practical support to carers when their circumstances change, for example when they:

- start or go back to work
- move from being a young carer to an adult carer
- have a change in benefits or financial circumstances
- go through personal changes (such as divorce)
- take on another caring role
- go into hospital
- are bereaved
- become less able to care as they get older.

For recommendations about support and training for carers during transitions between hospital and home, see [the NICE Pathway on transition between inpatient hospital settings and community or care home settings for adults with social care needs](#), in particular

recommendations on [training for carers](#).

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

10 Support during end of life care

Information and support

Offer carers frequent opportunities for discussion and help them to understand information about the diagnosis and prognosis of the person they care for (with the person's consent). Use a sensitive manner during these discussions and avoid jargon.

Health and social care practitioners involved in providing end of life care should be competent to have conversations with carers about death and dying.

Practitioners should establish early contact with carers involved in providing end of life care. Discuss with carers how best to support them, taking into account that unsatisfactory early contact with health and social care services can have a long-lasting negative impact on carers involved in providing end of life care.

Health and social care practitioners, including home care workers, should recognise that carers can find it hard to accept help at home when they are providing end of life care and can find it invasive.

Provide continuity during end of life care with the same professional care staff wherever possible, so that the carer and the person they care for can build a relationship with the staff supporting them.

Encourage carers who are caring for someone near the end of their life to think about ways they can get support from their family, friends, employer and wider social network.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

Advance care planning

Involve carers in advance care planning if the person being cared for consents to this. For recommendations about involving carers in advance care plans for people who may lack mental

capacity, see [the NICE Pathway on decision-making and mental capacity](#).

When making an advance care plan that includes responsibilities for carers, consider the wishes of any current or future carers who have been named in the plan.

Ensure the carer has a clear understanding of their role as part of the advance care plan. Share advance care plans in a clear and simple format with everyone involved in the person's care.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

Providing care at the end of life

When managing medication and other care at the end of life, follow the principles of involving carers and the dying person described in [the NICE Pathway on caring for an adult at the end of life](#).

During a structured medication review, as described in [performing a structured medication review in the NICE Pathway on medicines optimisation](#), take into account:

- the person's, and their family members or carers where appropriate, views and understanding about their medicines
- the person's, and their family members' or carers' where appropriate, concerns, questions or problems with the medicines.

Help carers who are providing end of life care at home to access local services that could support them, including from local hospices. This could include:

- [replacement care \[See page 19\]](#)
- palliative home care
- practical support, for example to use equipment and adaptations
- additional help in the home.

Provide privacy and dignity for people dying in hospital and their carers. This could include offering them a private room or, if this is not possible, alternatives such as:

- private space
- space to keep personal possessions from home
- flexible visiting times and tailored arrangements for carers
- comfortable seating for the carer
- access to refreshments.

Give carers of people at the end of life up-to-date and accurate information and advice about financial, legal and logistical issues they need to address when preparing for or following the death of the person they care for.

Take account of the changing information and support needs of carers in planning for their own future when the person they care for dies. This should include discussing with carers how to address their own support needs after the death of a mutual carer.

See the NICE guideline to find out [why we made these recommendations and how they might affect practice](#).

11 Local authority and health and social care organisation responsibilities

See [Supporting adult carers / Supporting adult carers: local authority and health and social care organisation responsibilities](#)

12 Workplace responsibilities

Advice and support

Workplaces should make information available to their staff about ways in which they can support employees who need to balance caring responsibilities with work. See [the NICE Pathway on workplace health: policy and management practices](#).

See the NICE guideline to find out [why we made this recommendation and how it might affect practice](#).

Flexibilities to support employment

Workplaces should offer flexible working arrangements to enable staff to balance caring responsibilities with work, and other initiatives that support mental wellbeing for carers in line with [the NICE Pathways on workplace health: policy and management practices](#) and [promoting mental wellbeing at work](#).

Workplaces should ensure that staff with caring responsibilities have equal access to career development. At a minimum, workplaces must meet the requirements set out in the [Equality Act 2010](#) in relation to people with caring responsibilities.

See the NICE guideline to find out why we made these recommendations and how they might affect practice.

Carers' assessments

Anyone who is an unpaid carer for a family member or friend has the right to discuss their own needs with their local authority, separate to the needs of the person they care for. This is a statutory requirement under the Care Act 2014. Carers can discuss anything they think would help with their own health and wellbeing or with managing other aspects of their life, including their caring role. The local authority uses this information to decide what help it can offer.

Carer's assessment

Anyone who is an unpaid carer for a family member or friend has the right to discuss their own needs with their local authority, separate to the needs of the person they care for. This is a statutory requirement under the Care Act 2014. Carers can discuss anything they think would help with their own health and wellbeing or with managing other aspects of their life, including their caring role. The local authority uses this information to decide what help it can offer.

Carers' breaks

These services, which would include respite care, give carers a break by providing short-term care for the person with care needs in their own home or in a residential setting. This can mean a few hours during the day or evening, overnight, or a longer-term break. Carers' breaks may be one-off or more regular arrangements. They can also benefit the person with care needs by giving them the chance to try new activities and meet new people.

Carer support plan

If a carer is identified as having eligible needs following an assessment under the Care Act 2014, the local authority must provide a support plan that sets out how those needs will be met. The support plan must be developed in partnership with the carer and should set out the outcomes the carer hopes to achieve, including their wishes around providing care and accessing work, education and leisure. The support plan must be regularly reviewed.

Peer support

Peer support involves carers sharing experiences, practical advice and emotional support and improving their understanding of the options available to them and the person they care for. Peer support can take a number of different forms, including one-to-one friendships and support based on lived experience and contact through third sector organisations, support groups or

online networks. Peer support is often but not always provided by volunteers, for example volunteer befrienders.

Replacement care

Care that replaces the care normally given by a regular carer. It may be needed either on a planned basis or in an emergency. Replacement care may be offered by the local authority, if the person needing care has had an assessment and is entitled to care and support services, or if the carer is entitled to help. Otherwise, people may have to pay for it.

Glossary

Carers

(a carer is an adult (aged 18 or over) who provides unpaid care and support to a family member, partner or friend (aged 16 or over) because of a disability, health condition, frailty, mental health problem, addiction or other health or social care need)

Carer

(a carer is an adult (aged 18 or over) who provides unpaid care and support to a family member, partner or friend (aged 16 or over) because of a disability, health condition, frailty, mental health problem, addiction or other health or social care need)

Sources

[Supporting adult carers](#) (2020) NICE guideline NG150

Your responsibility

Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not

mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.