A social care needs assessment is suitable if you need help and support to look after yourself.

The Care Act 2014 (England), Social Services and Wellbeing (Wales) Act 2014 and the Social Care (Self-directed Support) (Scotland) Act 2013 are the various UK legislations which set out how people’s care and support needs should be met. These legislations explain what your local authority must do to assess your care needs and your eligibility for care and support. This is different to healthcare needs which are provided by the NHS. The local authority is the organisation which manages public services in your area.

A social care needs assessment is suitable if you need help and support to look after yourself.

For example, you may not be able to:
- get yourself dressed independently.
- get out of the house to shop for groceries or take part in leisure activities.
- keep in touch with friends and family.
- get a job or take part in education.
- clean your house or prepare meals.
- keep safe.
- manage your money.
Having difficulties with these daily activities is considered a ‘need’. Being unable to do something doesn’t necessarily mean that you can’t do it at all. It can include when you are:

- Unable to do something without assistance (including being prompted by someone else to do it).
- Able to do something without assistance, but it causes you significant pain, distress or anxiety.
- Able to do something, but it takes you significantly longer than would normally be expected.

You can refer yourself for a needs assessment by contacting social services over the phone or online. You can also ask for copies of the questions you will be asked.

**How to get a Social Care Needs Assessment**

You can self-refer for an assessment by contacting your local council or social services department. Alternatively, your GP, therapists or other professionals involved in your care can make a referral. Depending on the level of need you may be eligible for continuing health care funding.

- Social services have to assess your care and support needs. They need to make sure your well-being and independence is the focus of the assessment.
- Your needs could include supported housing, employment, support at home and social inclusion.
- You can discuss with social care to make sure you don’t need crisis support in the future, or to make sure your condition doesn’t get worse.
- All local authorities must use the same eligibility criteria.
- Your local authority should meet your eligible needs.

**Continued Healthcare Funding**

Children, young people and adults may be eligible for NHS continuing health care funds/care if the needs of the individual cannot be met by the existing service. Health professionals can complete an initial assessment before referring to a clinical commissioning group for a full assessment. All aspects of the person are considered including mobility, psychological needs, respiratory, continence, communication, cognition etc. If successful individuals will be granted a personal health care budget to fund specialist equipment, care, Personal Assistants etc. If not eligible then access to social services for a full assessment of need will be required.
Preparing for an Assessment

Before your assessment consider what is causing you problems or concern and what you would like to achieve to maintain or improve your well-being when you are relatively well but also when your OI is giving you a tougher time.

Things to consider are:

Daily Living Activities

1. Managing and Maintaining Nutrition
   - Consider the difficulties of preparing food. For example, difficulties standing for prolonged times, risk to injury while preparing food, lifting heavy pots, more likely to eat ready meals due to difficulty in preparing food.
   - Are there any changes to the kitchen kitchens and/or equipment that is/may be required for you to carry out tasks.
   - Explain the potential difficulties of using cutlery/crockery and how spillages can occur because of this.
   - Explain how it is items such as straws and lightweight crockery can be needed. For example, straws are used during times of fractures where they may need to spend a long time lying down.
   - Explain any issues you may have with swallowing/choking.
   - Also, bring awareness to the fact you may have difficulty chewing due to either jaw malalignments or dentinogenesis imperfecta (brittle teeth).
   - Do you need assistance/another person to prepare food for you and how often?
   - Do you manage do your own shopping, think about extra measures you take? For example can you cross a road safely, can you hear/see the traffic, can you reach the traffic light crossing button?

2. Personal Hygiene
   (such as bathing, showering, grooming and laundry)
   - Explain any difficulties of getting in and out of the bath/shower as well as washing your body and hair.
   - Are you able to squeeze toothpaste, shampoo etc
   - Explain the difficulties of toileting: can you get clothing on and off safely, can you transfer, can you clean yourself, can you reach the flush and toilet roll?
   - Discuss the issues of reaching certain areas of the body and difficulties of drying due to deformities, fatigue and pain. Do you need assistance with this?
Think about the equipment you use or feel you need (i.e. transfer board, hoists, grab rails, seat in shower etc).

Consider the amount of time and how tiring these acts can be, due to pain and further difficulties with this when you have fractures or breaks.

Do you need assistance if you are facing a difficult day or experiencing fractures and breaks?

Do you have adapted clothing, do you need assistance with difficult fastenings?

Do you need support with doing laundry/ironing?

3. Maintaining a habitable home environment

Can you manage to do all the household chores? (vacuuming, dusting, changing bedding, cleaning windows, washing dishes, gardening, emptying bins etc).

Think about how much support you need, how long it takes you to do tasks, and the time needed to recover due to pain and fatigue.

Do you use any equipment or supports to help with these tasks?

4. Being able to use your home safely

If you are a wheelchair user, do you have enough space to manoeuvre? Can you access all areas of your home?

Are there any steps/stairs that would cause concern?

Can you open your windows safely?

Do you need to use steps to reach things and is this safe?

Can you get in and out of your bed safely?

Do you use any equipment or have any adaptations in place or do you need any?

Would you be able to leave your home quickly in the event of an emergency e.g. fire.

Health Needs

Remember that the assessor may not be as well versed in the symptoms of OI as you are. You should take time to think about symptoms which effect you and write them down prior to the assessment. Below are things to consider:

Medical involvement: are you on any medications such as bisphosphonates and how helpful these are.

Surgical involvement-rodding, plates etc. and what this means to how you are now.

Highlight all physiotherapy and other therapies you are involved with to make daily life easier.
Explain that you may need assistance due to a higher risk of falling and difficulties with other aspects such as changing etc.

Explain your levels of pain medication. If you use alternative treatments then list them too.

All aids (including hearing aids) and adaptations you use or would like to use to help you with tasks should be considered throughout this process. These may be self-bought, NHS issued, or homemade. These could include: grab rails, helping hand grabbers, jar openers, electric tin openers, bath boards, wet room, sticks, rollators, wheelchairs, hearing aids - anything that is a way round doing something the ‘typical’ way.

Many people with OI can do all aspects of daily living and mobility but due to them being extremely slow, tired, in pain or unable to repeat the tasks then this can mean they need extra support.

Have a think about how fatigue may impact the timings of your everyday routine, does it take you longer to perform daily living activities? If so how much longer?

Many people with OI experience ‘windows of energy’ and ‘cumulative effects’ meaning they can only cope with bursts of activity and their energy levels will quickly drop. If this affects you to the extent that you cannot finish all your daily living activities independently, then you should make sure the assessor aware of this. The Royal College of Occupational Therapists has useful information on how to conserve your energy.

Explain how you are most of the time, but also the ups and downs. The assessor needs to know how care can increase or lessen depending on injury or pain levels etc.

Think about others who may help you in certain tasks. The assessor needs to know how you cope with mobility and daily living on your own and what difficulties occur. You should list even the smallest ways in which another person assists you in accomplishing a task.

People with OI may not be comfortable using all types of hoisting equipment due to the risk of fracture and support. This needs to be considered carefully and is a personal preference.
Keeping a Diary

A diary of your levels of ability, pain, fatigue and how you achieve daily tasks. This may be useful for several reasons:

- It may be helpful in answering any questions the assessor may ask relating to, for example, the frequency at which you experience injuries and under which type of circumstance you experience them.
- A diary will also help you paint a picture of the time frame throughout which your symptoms may vary and the extent to which they do so.
- Additionally, it may be helpful to record the help you receive from others, especially the smallest of tasks which you may not normally notice.

In addition to keeping a diary you may also want to think about:

What your needs are and how you think social care and support might help you.

For example, you may have needs relating to your self-care and you might want support keeping your house clean and tidy and preparing food. You could make a note of the tasks you need help with.

Outcomes that you want to achieve.

What are your wishes, hopes and plans for life? For example, you might want to keep in touch with family or friends, live in your own flat, get a job or manage your money.

What barriers are there to achieving your outcomes and plans for life?

Whether your needs are fluctuating.

For example, you may be feeling well and not in need of care and support as you prepare for your assessment, but it might be useful to think about how your condition has affected you in the past. This will help you plan for how it might affect you in the future.

Finally, many people with OI are used to telling people proudly what they can do. In this instance you are asked to point out where you need help. This can be an alien concept to fiercely independent people like those in the OI community. It may be useful to download the [Brittle Bone Society factsheets](#) to show the assessor.
During the Assessment
A social worker or occupational therapist from the council will ask you questions about how you manage day-to-day tasks. This can be face-to-face or over the phone. Assessments usually last at least an hour.

You may want to consider whether you want someone to support you in the assessment process, such as a family member, a friend or an independent advocate:

- If you find the assessment difficult to understand you may get an independent advocate. The Local Authority must arrange this if:
  1) you have substantial difficulty in dealing with the assessment, and
  2) there is no other suitable person to help you.
- A suitable person could be a friend or relative. A person who gets paid to care for you is not a suitable person.
- An advocate can help you with the assessment and speak on your behalf to tell the local authority about your needs.

Assessment Outcome

- After your assessment, the local authority will decide if you have eligible needs. If you do, they will give you a copy of their decision. They should also provide a copy to your advocate or carer.
- The professional who assessed you has to show how they have made the decision and what evidence they used to do this. They need to show how they have linked the three parts, your desired outcomes, the eligibility outcomes and the impact on your wellbeing.
- If you have eligible needs you will go on to the support and care planning stage.
- If the local authority decides that you don’t have eligible needs they should explain how they decided this. You can ask for a written record of how they made the decision.
- If you don’t agree with the local authority’s decision. It is important you know you can appeal and many appeals are successful. An advocate may be able to help you challenge a decision.

Challenge your need Assessment

You may want to consider whether you want someone to support you in the assessment process, such as a family member, a friend or an independent advocate: Find an advocate in your area (NHS).
Payment/Funding for Social Care Needs

- Your local authority has to arrange care and support for a person with eligible needs. Once they have carried out a needs assessment, they will decide whether or not to charge for the care and support needed. If the local authority decides to charge for care and support they must follow the rules set out in the Care Act.

- If the local authority provides you with support it must assess your financial circumstances and decide whether you need to pay for some of the cost. If you do, the local authority will give you a copy of the assessment and explain how the decision was made.

- Your financial assessment will generally be carried out at the same time as your needs assessment.

- The assessment will look at your income and your capital. They will take into account whether you’re supported in a care home or not. Different local authorities may charge differently and you can ask for a copy of their charging policy.

- You can read more about the financial assessment process here.

Please note: once the financial assessment is complete and you know how much you would need to contribute to your care costs, YOU decide if you want to go ahead.

Useful Links

Disability Law Services- Is a national charity that gives free legal advice about community care and employment discrimination to disabled people, their families and carers.

Disability Rights UK- Provides information on social care funding, direct payments and personal budgets.

Contact- Gives advice, information and support for families of disabled children

Scope- Provide useful resources and advice about adult social care.

Scottish Government- Personal and Nursing Care for people living in Scotland.

Northern Ireland- Arranging Health and Social Care.

Social Care Wales- Information and Learning Hub

If you found our factsheet helpful and would like to support the BBS in continuing to provide resources, you can donate by scanning our QR Code.