

**Helpful Hints and Tips**

**The Care Act 2014 – are you getting what you are entitled to?**

ASUK has produced this ‘Helpful Hints and Tips’ for families and individuals to help navigate the benefits and assessment entitlements. We hope you find it useful.

**The Care Act 2014 – your right to specialist assessment**

Many families and individuals who are affected by Alström Syndrome know what they are entitled to by law. Others are not so sure, especially after the law changed last year. So we wanted to give you brief information which may help you decide whether your needs have been properly looked into and provided for by your own Local Authority. With apologies to those outside England this information relates to English law only – Wales has its own guidance and we can advise accordingly.

**This information is for those over 18 years of age** – If your child/young person has not been assessed please let us know if you need support, as the guidance is slightly different, particularly around the level of expertise the assessor holds. For example, in England any assessment of a deafblind/multiple sensory impaired child must link up with an assessment of Special Educational Needs. For those approaching 18 years old the Care Act now includes ‘transition assessment’.

If you need this information in another format, or if you have any questions or issues please ask us, as we recognise every person and family is unique.

**The Care Act 2014**

The Care Act 2014 replaced previous laws (often referred to as Section 7 Deafblind Guidance) and is considered to be stronger for people who have sight and hearing loss, as well as the other complications associated with Alström Syndrome.

Under the Care Act, special deafblind guidance has been issued to Local Authorities called ‘Care and Support for Deafblind Adults and Children’.

We know that the word ‘deafblind’ can be difficult for some people – it doesn’t mean someone has lost all their sight or all of their hearing – so most people who are affected by Alström Syndrome may be described as deafblind within the law. The important point is that even a small loss in sight and hearing together can give challenges in everyday living, especially with communication, accessing information and mobility.

**What does the Local Authority have to do by law?**

The most important areas for you to know are that Local Authorities have to:

* Make an assessment of need for support – needs may include providing care, equipment, access to the community (Personal Assistants, Communicator Guides, intervenors) and information and advice
* Make sure the person carrying out the assessment MUST be suitably qualified and deafblind trained in line with the Care Act 2014. Generally, it is not acceptable to use separate assessors such as one related to hearing impairment and another for visual impairment from two separate teams. The authority may not have suitably qualified staff themselves so may need to use outside organisations with suitably qualified staff. It is very important to check this
* Ensure when services are provided they may need to be specific to dual sensory loss, rather than hearing loss or vision loss as single sensory impairments
* Carry out an assessment, if you request it (subject to being eligible through dual sensory loss and other complex needs).The authority cannot say that it does not have sufficient funding or that your financial situation is too high for them to do an assessment. If you are refused an assessment, please let us know so that we can check or help you check that the authority has a good reason

**How does an assessment work?**

The assessor will meet you at your home (this may be once or several times). They should discuss and look at your access to the local environment. The assessor must be either a deafblind qualified social worker or a qualified assessor from an outside organisation, commissioned by the Local Authority. The assessor will usually use an assessment form – you can ask for a copy in suitable format (large print, Braille) before the meeting, to help you consider the questions in advance. We always encourage a positive attitude around what you can do, however you may need to speak specifically about any difficulties you have on ‘bad’ days.

The assessment should look at your needs in the following areas and recognise that this may change at different times (within a day, a month, at different times of year or weather conditions):

• Communication

• One-to-one contact with people

• Social interaction and accessing the community

• Support with mobility

• Assistive technology

• Rehabilitation / mobility

• Your current and possible future needs

The assessment should be ‘carer-blind’ which means that needs are assessed as if the person, usually a family member, is not available so that if, for example, the family member is taken ill there is still sufficient support in place.

The assessment should also look at how Alström Syndrome affects various areas of your life and how this affects your general wellbeing. For example, if in the past you have been unable to join activities you wanted to do outside the home, then this must be part of the assessment and care plan process, to see if there is a way to do things with the necessary support / equipment.

The assessor writes a report which shows the full extent of your needs. The assessor reports on your ‘eligible needs’.

This may include:

* Specifically trained one-to- one support workers (Personal Assistants, Communicator Guides, Intervenors)
* Home care help with things like cleaning and shopping where visual loss makes this difficult
* Equipment for the home – this should allow for sight and hearing loss rather than separate provision which doesn’t take account of your eligible needs. For example, we hear of Deaf Services giving a doorbell with a flashing light or a Visual Impairment team giving a doorbell with a loud alert when together they should have given a bell with a tactile alert.
* Technology equipment and support
* Recommendations and information about local service provision and networking
* Mobility training
* Teaching daily living skills over a suitable time period e.g. 6 weeks
* Communications skills

If you would like one of the ASUK team to be there with you for the assessment, please talk it through with us in advance of the meeting to enable us to plan the visit.

**After the assessment report?**

A suitably qualified person then decides for the Local Authority whether your needs meet the eligibility criteria. The eligibility criteria includes the following outcomes – you may be able to do some, but not always in a safe, timely way or without stress.

You will have an eligible need if two or more of the following outcomes are not met:

* Managing and maintaining nutrition – for example if you have difficulties shopping, cooking, identifying food labels and instructions
* Being appropriately dressed – for example choosing clothes by colour, dress appropriate to the weather, clothes that need washing or mending
* Being able to make use of the home safely –for example you may need vibrating smoke/fire alarms or doorbells; improvement to lighting to avoid falls and safe movement around your home
* Maintaining a habitable home environment – e.g. keeping the house clean, hygienic and hazard free; being able to manage paying your bills
* Developing and maintaining family and other personal relationships – for example is it difficult for you to communicate or get out to meet friends; difficulty in using the phone or email
* Accessing and engaging in work, education, training and volunteering. For example are you receiving support and information in ways that are suitable for you to understand and join in?
* Making use of necessary facilities or services in the local community including public transport and recreational facilities and services. For example can you go swimming, are there ways for you to keep fit and active?

**The care and support plan**

A budget will have been given which is an estimate of meeting your care and support needs before the care plan is put together. This may be low if a Local Authority uses what is called a Resource Allocation System (RAS) to decide an available budget – the Care Act says that this may not be used where needs are complex or costly to meet, because the person is deafblind. If the estimated budget seems impossibly low let us know as we can help check if RAS has been used.

Together with you, the qualified person who carried out the assessment should be involved in helping to draw up your care and support plan. This is so that you have control and influence over the plan and may use the person’s expertise to come up with solutions you may not know about, for example technological equipment.

**Decision on funding**

The care and support plan MAY go to a panel which must include your assessor (or a similarly qualified person).

The Local Authority will then decide on a Personal Budget to meet your needs.

If the cost of services is higher because they do not have qualified staff, such as dual sensory qualified Personal Assistants, then they should increase the budget. This is instead of expecting you to take fewer hours or a lower paid unqualified worker who may provide an inadequate service if, for example, they do not know how to sight guide safely.

They will either pay for some or all of the services themselves or offer you Direct Payments where you make your own decisions about equipment and services.

**What are the advantages?**

New rules in the 2014 Care Act allow you to take the lead in explaining what care and support you need to make life easier for you. The Care Act places your wellbeing at the centre of your support needs.

If you have your own finances, over the thresholds there may be no financial contribution from the Local Authority. However, the assessment will give you the chance to discuss your needs with a health or social care professional who can advise you on what help is available.

**What are the disadvantages?**

* Being assessed can feel intrusive. However, our experience is that if someone is suitably qualified they have a real interest in your needs and you can tap into their expertise for ideas even if, in the end, there is no provision of service
* It can be a battle - we are very aware that Local Authorities are varied in their provision and some ignore the spirit of the Care Act or are under enormous financial pressure. We do not know what the effects of recent political changes may be but we have to work in the present. We believe in the need for Care Act provision for people who are affected by Alström Syndrome. Some families are very good at making their own cases (any tips welcome!), while for others we are very happy to support you in seeking the correct levels of service
* The amount the Local Authority is willing to pay depends on your finances. Once your Local Authority has carried out your assessment and worked out what services you need, they’ll carry out a financial assessment. This is called a ‘means test’. This looks at your regular income (pensions, benefits or earnings) and your capital (cash savings and investments, land and property and business assets). However, your home won’t be counted as capital if family or close relatives (meeting certain conditions) live there as well as you. The threshold in England is £23,250. This help you work out if you need to contribute towards the cost of your care and support plan, and whether the Local Authority will pay for all or some of your costs.

**How to get an assessment?**

If you have already had an assessment it may have been a standard social care needs assessment but not a specialist deafblind assessment. If you are in doubt, contact us for advice.

If you have had an assessment in the past few years but your needs have altered, perhaps because your sight has changed or another condition has affected your needs, then you are entitled to ask for a new assessment. In any event, any existing care plan should be reviewed annually and within the Care Act guidance.

Contact your Local Authority adult social services department, if you need support to do this let us know. Request a deafblind specialist assessment which is compliant with the Deafblind Guidance issued under the Care Act 2014. Remember, the Local Authority cannot refuse to do this on the grounds of your finances or their idea of your need prior to assessment.

**Personal Health Budgets (PHBs)**

We are currently awaiting guidance on a new option which MAY apply to people who are affected by Alström Syndrome. A personal health budget is an amount of money to support a person’s health and wellbeing needs, planned and agreed between the person and their local NHS team. The idea is to enable people with long-term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive. Personal health budgets are very new so the process is still being developed. We are very fortunate that Jane Lodwig, formerly the clinical nurse at the Alström Syndrome adult clinics is now working directly with PHBs and we hope to receive updates from her and will let you know if this will apply.

**If you would like to share your own experience of the assessment process, please email us. It is helpful to share ideas, especially about how people have argued their case and obtained a good care package. We know it is easier in some areas of the country than others and we can all learn by sharing. This is about rights not about continually having to fight for basic human rights.**

This information is part of a series that we will be producing to help individuals and families. Please let us know any topics which would be most helpful for you and your family and we will compile information onto our website and in each newsletter. You can do this by either emailing Catherine at Catherine.lewis@alstrom.org.uk or calling 01803 613117. We are always pleased to hear from you.

Please share this document or print it out for any family members and/or professionals who are involved in supporting people who are affected by Alström Syndrome.

You are welcome to use this series of helpful hints in any training or presentations, all we ask is that you acknowledge ASUK as the source.

Please visit our website [www.alstrom.org.uk](http://www.alstrom.org.uk) for more information

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***Strength for today, hope for the future***

