

Information, Advice and Hear from the Alström Community

ASUK would like to assist you to be able to find the right support for you and your family, as we know from our experience how complex this can often be. We've brought together helpful information, mainly from online resources that we think you will find useful. We've grouped these into topics to make it easy for you to quickly find the resources you need.

Further down the page, you will also find short films from both families and professionals, giving further insights and experiences from the Alström community.

If you would like advice on a specific topic which isn't included please let us know so we can develop our resources further.

Don't forget our family support team are here to assist you, so please get in touch. All contact details and team information can be found on the 'Meet the Team' page [HERE](#)

If you have any further questions please contact catherine.lewis@alstrom.org.uk / 07970 071 675

[Latest Guidance on the Coronavirus](#)

Corona Virus

This is the advice from NHS England and the links to the latest information.

Everyone is being reminded to follow Public Health England advice to:

- Always carry tissues with you and use them to catch your cough or sneeze. Bin the tissue and wash your hands or use a sanitiser gel.
- Wash your hands often with soap and water, especially after using public transport.
- Use a sanitiser gel if soap and water are not available.
- Avoid touching your eyes, nose and mouth with unwashed hands.
- Avoid close contact with people who are unwell.

You can click on the link to find Public Health England's advice for protecting those in vulnerable groups, such as Rare Diseases.

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

If you live in Wales, the government's advice on shielding can be found here: <https://gov.wales/guidance-shielding-and-protecting-people-defined-medical-grounds-extremely-vulnerable-coronavirus-0>

If you live in Scotland, the government's advice on shielding can be found here: <https://www.gov.scot/publications/covid-shielding/>

If you live in Northern Ireland, your guidance around shielding can be found here: <https://www.nidirect.gov.uk/articles/guidance-shielding-extremely-vulnerable-people>

You can find information and advice from Public Health England at <https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public>

You can find out more about the Government's response on their website www.gov.uk/coronavirus

NHS Guidance can be found by following the link to the NHS website <https://www.nhs.uk/conditions/coronavirus-covid-19/>

There is also an easy read leaflet which can be downloaded [HERE](#)

Talking to your children about Coronavirus

The Mental Health Foundation have produced an article about 'how to talk to your child about the Coronavirus' this can be viewed [HERE](#)

There is also a simplified easy read guide which can be downloaded [HERE](#)

The charity Young Minds have also produced ten tips from their parents helpline about talking to your child about the Coronavirus, you can discover these tips [HERE](#)

For younger children, the CoviBook describes the Coronavirus in a child friendly way, that doesn't represent the science but more about the child's emotions that they may be feeling currently. Check out this book online [HERE](#)

Beyond Words

Beyond words produce picture only stories to explain and explore topics, such as coping with the coronavirus and explaining to others who may find it difficult to understand.

You can find their resources via this link <https://booksbeyondwords.co.uk/coping-with-coronavirus>

Webinars

During this time we have turned to a virtual world to stay in touch with family and friends.

To keep the Alström community in touch we have been doing a range of webinars on relevant topics and some 'cuppa and catch ups' so everyone can keep in touch.

1. Let's talk – covid-19 Q&A
2. Let's talk – keeping healthy and active
3. Cuppa and catch up – Keeping Entertained
4. Let's Talk – Discovering Diabetes
5. Let's Talk – Healthy Hearts
6. Let's Talk – Shielding Guidance
7. Let's Talk – Life after Lockdown
8. Let's Talk – Back to School
9. Let's Talk – Next steps for Clinics
10. Let's Talk – Healthy Minds, Healthy You

[Things to Think About & Support](#)

This check-list is a good starting point to think about what you need now, what you might need in the future and how you will go about getting this.

- **Have you registered?**

Register if you have a medical condition that makes you extremely vulnerable to coronavirus. For example, you'll be able to ask for help getting deliveries of essential supplies like food. If you're not sure whether your medical condition makes you extremely vulnerable, register anyway.

You can register yourself, or for someone else.

Before you start

You'll be asked for your NHS number (but you can still register if you do not have it). You can find your NHS number on any letter the NHS has sent you or on a prescription. This service is available in England. If you do not live in England, there's guidance for:

- [Northern Ireland](#)

- [Scotland](#)
- [Wales](#)

<https://www.gov.uk/coronavirus-extremely-vulnerable>

- **Groceries and Supplies:**

Do you have enough supplies currently and do you have a way to get food delivered?

RNIB have produced some essential links and information about supermarkets revised opening times for vulnerable people, along with some helpful tips about how these areas may be changing to protect us all and how to get a sunflower lanyard if your disability is hidden <https://www.rnib.org.uk/connect-community/connect-news-and-stories/essential-links-and-information-supermarket-opening-times>

- **Work:**

Can you carry on working, including working from home? If not, can you find out your rights to payment or benefits?

- **Medication:**

Do you have enough medication?

Do you know how you can get more?

Top Tips:

- You should continue to get your supplies from your local pharmacy
- Order your prescriptions in good time
- You should be able to order online or by telephone
- Always best to phone your pharmacist first to check your medication is there and ready
- Your family member should get these for you or have them delivered to you at home

- **Health:**

Can you reorganise any planned therapy or treatments?

Do you know the numbers to call if you need further advice?

Call NHS 111 if you have an urgent medical problem and you're not sure what to do.

Call 999 if you are breathless or need emergency medical attention

- **Connectivity:**

Have you got ways to keep in contact with people you see regularly, like their phone numbers, email addresses?

Do you need help setting up digital communication, like a video calling app?

- **Routine:**

Can you create a routine or timetable for yourself?

And if you live with other people, should you create a household schedule?

Do you need to agree how the household will run with everyone at home all day?

- **Exercise:**

Is there any physical activity you can do inside your home, like going up and down the stairs, using bean tins as weights, or exercises you can do in your chair?

There are lots of online exercise routines and ways to stay active.

- **Nature:**

Do you have a garden you can exercise in?

What about bringing nature into your home, with house plants or flowers?

Could you do some gardening?

- **Entertainment:**

Have you thought about how to keep yourself entertained?

What about those titles you have always wanted to read or TV shows you have always wanted to watch?

- **Relax:**

Have you got what you need to relax?

What about learning mindfulness techniques or creative writing or drawing?

Covid 19 Mutual Aid UK

This a group of volunteers supporting local community groups organising mutual aid throughout the Covid-19 outbreak in the UK. They focus on providing resources and connecting people to their nearest local groups, willing volunteers and those in need. You can find out where your nearest local group is by visiting their website [HERE](#)

Check out these resources on these pages to help with this check-list and if there is anything you would like specific information on, please get in touch.

Also, if we have missed any useful information or resources which you think other families would benefit from, please let us know and we will add these to our information.

[How do I know the information is reliable?](#)

There is a huge amount of information about Coronavirus and what we should all be doing to stay healthy during this pandemic. How do you know the information you are reading is reliable.

There are 4 sources of information which we use to gain the latest information and guidance. These are:

The Government website which can be viewed [HERE](#)

The BBC News website which can be viewed [HERE](#)

The NHS website which can be viewed [HERE](#)

Public Health England website which can be viewed [HERE](#)

[Looking After Yourself](#)

There are lots of websites looking at how we can stay fit and healthy but what about our mental health and wellbeing. The websites below provide information about how to look after yourself during the difficult time.

The Mental Health Foundation

The Mental Health Foundation provide information about good mental health for all and one article I am sure would be helpful for many families 'how to talk to your child about the Coronavirus'.

Find out more about the Mental Health Foundation [HERE](#)

You can also find the article about 'how to talk to your child about the Coronavirus' [HERE](#)

Every Mind Matters

The NHS, Every Mind Matters project offer practical tips to help you look after your mental health and wellbeing, you can view their top tips [HERE](#).

Young Minds

The charity Young Minds, offer a blog for young people which is full of personal accounts and information about how to keep yourself safe and healthy at this time, take a look on their website [HERE](#)

The BBC

The BBC have brought together some useful resources in this article 'Coronavirus: How to protect your mental health', which can be viewed [HERE](#)

Mindfulness

You may have heard people mention 'Mindfulness' and wondered what is it really all about.

Why not try this Every Mind Matters breathing exercise, it only takes a few minutes and will help you feel calm:

<https://www.youtube.com/watch?v=wfDTp2GogaQ&app=desktop>

Stay Connected

At this time when we are faced with staying indoors, it is more important than ever to stay connected.

ASUK will be offering regular webinars where the AS community can come together to share their experiences and offer a range of useful topics to discuss. We may even explore doing a community quiz!

Also, through your Family Support Worker you can link to them either via a phone call or we can use a webinar facility so you can talk to each other in a virtual get together online.

Gather together your friends and families email and phone numbers to ensure you can call them if you need support and to catch up so you can stay in touch.

Social Media

Social Media is a good way to keep in touch with communities such as Facebook and Twitter.

HouseParty

There is also a relatively new app called '**HouseParty**'. Houseparty is a video-focused social network app, the app can bring together people to create social reactions with up to 8 friends (and friends of friends) at the same time, via live video and texts allowing only users to add people they already know via Facebook or their device's contacts list.

Creating an account with Houseparty is simple, all is needed is a username and you can also add your phone number to give the app access to your contact list. This automatically allows you access to anyone on your list, but entering your phone number is optional. Users can also manually enter the Houseparty username of anyone they wish to chat with.

Chat requests are sent out to friends via notifications through the app or through text messages. As soon as a friend responds, the video chat is ready to begin. The real-time accessibility of this app allows friends to enjoy each others company as though they were all in the same room.

The app is recommended for children aged 12+ but for all ages if you are using these apps, remember to check the privacy settings and if you use HouseParty that once a 'party' is set-up that the virtual room is locked so other people can't pop in.

Advice for parents

- Make sure they 'lock' their chat room.
- Use the Houseparty security features – using those mentioned above can help protect your teen.
- Advise your teen to use a different password to others they are currently using.
- Discuss with your teen the dangers of adding people they don't know or accepting requests from people they don't know.
- Always check with your teen about who they are chatting with and what types of conversations are taking place.
- Set up parental controls on their devices to control the level of security.
- Talk to your child about building up their digital resilience and critical thinking – as another way to highlight the need to help them cope with whatever the online world throws at them.

You can find out more about the app [HERE](#)

Zoom

You may have heard of '**Zoom**' this is a way you can keep in touch with your friends and family on a 1-1 video call or in groups of up to 100 people! – you can sign up for free [HERE](#)

Get in touch

What do you use to keep in touch with family and friends?

Do you use apps which you have found to be accessible and good to keep in touch with your loved ones?

Let us know so we can circulate to other families who may be feeling isolated as this time.

Stay Well and Stay in Touch!

[Keeping Fit and Healthy Indoors](#)

There are lots of workout videos and resources for you to stay fit and healthy whilst remaining indoors.

Check out **Joe Wicks** You Tube fitness channel, he offers workouts for all ages including PE sessions at 9am Monday – Friday and as many of you may have found out these sessions are not just for kids, and are a real intensive workout for all.

<https://www.youtube.com/channel/UCAxW1XT0iEJo0TYIRfn6rYQ>

The **NHS** provide a range of fitness studio exercise videos

<https://www.nhs.uk/conditions/nhs-fitness-studio/>

The **BBC** have resources to ‘Get Inspired’ and working out at home without any equipment

<https://www.bbc.co.uk/sport/get-inspired/32416767>

Do any of you remember the Green Goddess or Mr Motivator?

We'll check out the Green Goddess in action on the BBC News, showing us how it is done now... and there is talk that Mr Motivator may be making a comeback too, watch this space...

<https://www.bbc.co.uk/news/av/uk-51959557/coronavirus-the-green-goddess-returns-with-self-isolation-fitness-tips>

British Blind Sport offers a range of accessible exercise work-outs including yoga and mindfulness <https://britishblindsport.org.uk/stayinworkout-pilates-yoga-stretch/>

[Keeping Entertained!](#)

There are lots of ways to keep the children entertained, check out some of the resources below:

Discover the Joy of Reading

Amazon Audible

Is offering free audio books which can be listened to on your laptop, desktop, tablet or phone. The titles are available in 6 different languages.

<https://stories.audible.com/start-listen>

David Walliams

Will be releasing a free audio story every 30 days, check out the website [HERE](#)

Unite for Literacy

Reading is a fantastic way to learn about the world around us and engross yourself in a good book. Unite literacy offers an array of books online which can be narrated in a choice of languages

<https://www.uniteforliteracy.com/>

Living Painting

The charity Living Paintings create tactile and audio books for people who have visual impairments, called them Touch to See books for all ages. These are distributed through a free postal library.

<https://www.livingpaintings.org/>

RNIB

The charity RNIB offers a library service which is absolutely free, in a range of formats including Talking Books, Braille or Giant Print. Ensuring everyone can get lost in a good book.

<https://www.rnib.org.uk/books>

Calibre Audio Library

The charity lends audio books and streams books online for anyone who struggles to access print, including children. Find out more information on their website [HERE](#)

Home Learning

Free **home learning** resources for all ages of children

<https://allinonehomeschool.com/>

Cool Maths

If your little ones, love their numbers then why not head across to Cool Maths 4 Kids where lots of fun activities will keep your genius's entertained.

<https://www.coolmath4kids.com/>

Learn maths with Carol Vorderman, her website services are now free!

<https://www.themathsfactor.com/>

National Geographic for Kids

This website provides lots of creative activities, competitions and fun facts for all ages to have a go at.

<https://www.natgeokids.com/uk/>

Twinkl as lots of educational activities for all ages and also some sensory stories and resources.

<https://www.twinkl.co.uk>

Fun Science and Technology

Science Kids brings an online resource of science activities, including games, quizzes, videos, cool facts and lots more to keep your budding scientists entertained. Here's some jokes to keep you giggling

'Why do tigers have stripes? So they don't get spotted.'

'What do astronauts do when they get angry? Blast off!'

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‘What do you call two dinosaurs that have been in an accident?

Tyrannosaurus wrecks’

<http://www.sciencekids.co.nz/>

Dekko Comics

To help with home learning Dekko comics are offering their fun and educational comics free online. They offer over 140 comics to help with maths, english, science, history, geography and PSHE.

<https://dekkocomics.com/issue-list-home>

Learn Something New

What about learning something new, like Sign Language?

British Sign Language (BSL) online course reduced to £3 for under 18s

<https://british-sign.zendesk.com/hc/en-us/articles/360044794654>

<https://www.british-sign.co.uk/learn-online-british-sign-language-course/>

Time to Play!

Play tool kits

The charity **Sense**, offer a range of play tool kits to support children of all abilities to join inclusive activities. There is also a series of helpful video guides on how to make play inclusive and accessible.

<https://www.sense.org.uk/get-support/support-for-children/play-toolkits/>

Soundabout Live – Bring a tambourine, shaker or some pots and pans to rattle and shake.

Soundabout Live! sessions will run at 2pm on Tuesdays and Saturdays led by different members of the music practitioner team.

<https://www.facebook.com/SoundaboutUK/>

Time to Dance!

Flamingo Chicks offer inclusive dance classes so everyone no matter what their ability can enjoy dance and movement. They are now offering virtual classes for you to explore. They look great fun!

They even offer relaxation videos for parents/carers, sensory activities and lots of useful resources.

[FC at home](#)

Silver swans are free online ballet exercise classes mainly aimed at the older generation, but anyone can give it a go!

Cosmic Kids Yoga and Mindfulness, not just for kids – these look great fun.

<https://www.youtube.com/channel/UC5uIZ2KOZZeQDQoGsiqbQ>

British Blind Sport offers a range of accessible exercise work-outs including yoga and mindfulness <https://britishblindsport.org.uk/stayinworkout-pilates-yoga-stretch/>

Like going to the Theatre?

The National Theatre are offering productions from the comfort of your own home, how fantastic – every thursday they offer full length theatre plays for you to view online.

<https://www.nationaltheatre.org.uk/nt-at-home>

The Royal Opera House invites adults and children to explore the theatre with their fun resources and videos online

<https://www.roh.org.uk/>

The show must go on! – Full length performances of Andrew Lloyd Webber's productions are launched every Friday at 7pm (BST), which can be watched for 48 hrs on you tube.

<https://www.youtube.com/theshowsmustgoon>

Who doesn't love a freebie?

Lots of companies that often charge monthly fees for their services are wavering these to try and keep the country entertained. I suppose as well they are hoping that you will continue with the subscription afterwards too. Check out the Money Saving Expert link [HERE](#) where you can get free lessons to learn a language, listen to ballet and opera broadcasts or even free homeschooling lessons from Carol Vorderman!

[Discover a World Online](#)

After a few weeks of reading all those books you have always wanted to and caught up with all the TV series you never get chance to watch, maybe you are now looking for some culture, something a bit different to do.

Now you can visit a museum or art gallery without even leaving the comfort of your couch.

The British Museum, London

Go to the link to find virtual tours, which are audio described too click [HERE](#)

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Buckingham Palace, London

Go to the link to find virtual tours [HERE](#)

Guggenheim Museum, New York

Google's [Street View](#) feature lets visitors tour the Guggenheim's famous spiral staircase without ever leaving home. From there, you can discover incredible works of art from the Impressionist, Post-Impressionist, Modern and Contemporary eras.

Musée d'Orsay, Paris

You can take a virtual tour through this art gallery to discover many famous French artists, click [HERE](#) to discover more.

Van Gogh Museum, Amsterdam

You can virtually visit this museum by clicking [HERE](#) and discover the largest collection of artworks by Vincent van Gogh, including over 200 paintings, 500 drawings, and over 750 personal letters.

Vatican Museums, Rome

Welcome to the Vatican museums, the gardens, villas and surrounding area, with these 360 virtual tours you feel like you are there, discover all [HERE](#)

Natural History Museum, London

Discover the wonder of nature at the Natural History Museum, click [HERE](#) to enter the museum and discover fun facts, tours and activities.

[Ramadan at home](#)

WHAT IS RAMADAN?

In 2020, Ramadan will be from around the 23rd/24th April for 29/30 days. It is the holiest month of the year for Muslims as it is when the Qur'an was revealed to the Prophet Muhammad (PBUH).

During the month of Ramadan, Muslims around the world will fast, meaning they won't eat or drink between dawn and sunset.

Fasting is important during Ramadan as it allows Muslims to devote themselves to their faith and come closer to Allah, or God.

Fasting is one of the Five Pillars of Islam, which form the basis of how Muslims live their lives.

Ramadan is also a time for spiritual reflection, prayer, doing good deeds and spending time with family and friends.

Normally, people will make a special effort to connect with their communities and reach out to people who need help.

COVID19 – #RAMADANATHOME

Ramadan 2020 will be a very different experience for Muslims all over the world during the COVID19 lockdown in accordance with public health advice.

At present, it is unlikely that social distancing measures will be lifted and we will be able to return to our normal routines. As such, acts of worship for Muslims outside of the home will still be suspended to stop the spread of the virus.

It is common to have a meal (known as the suhoor) just before dawn and another (known as the iftar) directly after sunset.

At the end of the fast – when the sun has gone down – usually, families and friends will get together for iftar to open their fast in the evening.

The Muslim Council of Britain are advising families and friends to video call each other during iftar this year during lockdown.

Many Muslims also usually go to the mosque to pray, when lockdown restrictions aren't in place.

Some mosques have been holding virtual services online for people to watch together.

The Muslim Council of Britain offers further information about Ramadan and guidance and factsheets on their website click [HERE](#) to find out more.

Ramadan and Diabetes

Diabetes UK provide information about how to stay healthy if you have diabetes and are fasting during Ramadan.

They offer tips on reducing the risks of becoming ill if you decide to fast and when it's advisable not to fast.

You can download their factsheets about fasting and managing your diabetes during Ramadan, developed in partnership with the Muslim Council of Britain's Diabetes Advisory Group.

You can view the information and download the factsheets from Diabetes UK on their website [HERE](#)

What happens at the end of Ramadan?

There is a special festival to mark the end of Ramadan. This is called Eid al-Fitr – the Festival of the Breaking of the Fast.

It begins when the first sight of the new moon is seen in the sky.

Muslims will not only celebrate the end of fasting, but will also thank Allah for the help and strength that they were given throughout the previous month.

During Eid ul-Fitr Muslims dress in their finest clothes, give gifts to children and spend time with their friends and family. Muslims will also give money to charity at Eid.

All about section

[1. All about Health and Wellbeing](#)

Please find below information and website links to further organisations who can give specific advice and guidance regarding some of the specific areas which can affect those who have been diagnosed with Alstrom Syndrome.

Don't forget that your Family Support Worker can also advise, get you in touch with the right people and make contact with the Alstrom Syndrome specialists in Birmingham if you have any specific questions relating to Alstrom.

If you have an immediate health concerns please visit your GP or Consultant in your local area and for all emergencies your first point of call should be your local A&E department or to call 999.

All about the eyes

The eyes are often the first indication that you may be affected by Alström Syndrome.

Children who are affected may have an involuntary rapid movement of the eyes, which is referred to as Nystagmus or wobbly eyes and extreme photophobia which is a extreme sensitivity to light.

Eyesight can often deteriorate during childhood but the progression of vision loss is different from person to person. Often dark glasses are used both indoors and outdoors to combat photophobia. We support the need to teach IT and Braille at an early age as possible.

Some of the organisations below provide further information and advice:

[NHS](#)

The National Health Service (NHS) provide information about vision loss and organisations which give you information and support.

[Nystagmus Network](#)

A UK charity offering support and information for people affected by nystagmus (*wobbly eyes*).

[SeeAbility](#)

Are a charity who provide specialist support, accommodation and eye care help for people with learning disabilities, autism and sight loss. They also provide useful eye care fact sheets.

[RNIB](#)

The Royal National Institute for the Blind (RNIB) charity offer a wide range of services and information relating to sight loss, including an online community and help-line.

[RSBC](#)

The Royal Society for Blind Children charity provide a range of services in London and across England and Wales for blind and partially sighted children and young people, their families, and the professionals who work alongside them.

[Sense](#)

The charity sense offer a wide range of services for those who are affected by both vision and hearing loss. Including information, support, family events and sense colleges and day centres.

[Visualise](#)

Visualise work with organisations to increase awareness of the accessibility challenges faced by employees and/or customers with disabilities. Founder, Daniel Williams, who has an eye condition called Retinitis Pigmentosa which causes gradual sight loss, established the business in 2014 in order to share his knowledge, skills, experience and expertise in this field. Click [HERE](#) for the Visualise resource pack designed to help people facing sight loss – it provides lots of useful information about support services and suppliers of assistive technology and equipment.

All about hearing

Hearing loss can occur for people affected by Alstrom. This varies greatly from person to person and should be checked regularly. Hearing aids can help considerably and a small number of adults have been treated successfully with cochlear implants.

[Action on Hearing Loss](#)

The charity support people across the UK to manage their deafness, tinnitus and hearing loss. Providing information and community-based care and support services and campaigning for equality. They also offer comprehensive factsheets about cochlear implants and how to get hearing aids and how to adjust them, click [HERE](#) to view these.

BID Services

Are a charity who offer support for children, young people and adults and their families and carers, who are deaf, hard of hearing, visually impaired or have a dual sensory loss. Their services include advocacy, employment and housing advice and specialist equipment advice and mobility training.

All about dual-sensory loss

Deafblind UK

Offer support for people affected by dual sensory loss, both hearing and sight loss. they offer a comprehensive guide to both hearing and sight loss, getting the benefits you are entitled to and also provide a range of services such as activities and events.

Sense

The charity sense offer a wide range of services for those who are affected by both vision and hearing loss. Including information, support, family events and sense colleges and day centres.

All about the heart

Alstrom can cause the heart muscle to pump less efficiently. This is known as cardiomyopathy. This often occurs in infancy but the heart often recovers, although not completely, and can reoccur or present for the first time in later life. It is important for all people affected to have an annual cardiac review.

Cardiomyopathy UK

Offering information and support for people affected by Cardiomyopathy. Please note that people with Alström Syndrome are much more likely than average to recover from this condition.

British Heart Foundation (BHF)

Offering advice and support regarding different types of heart conditions, including healthy recipes to try.

All about Diabetes

Insulin resistance is often present from infancy, but progression to type 2 diabetes is influenced by lifestyle. This can be impacted by increase in appetite, gaining weight more rapidly and restrictions around exercise due to dual-sensory loss. A healthy lifestyle including a healthy diet and exercise is very important in the overall management of Alström.

Diabetes UK

Offering support and information to people affected by Diabetes including useful resources such as living a healthy lifestyle, recipes and research developments.

All about our wellbeing and mental health

[Preparing for Adulthood](#)

Providing resources and information for young people who are affected by disabilities as they move into adulthood. They offer specific expertise and support with paid employment, good health, independent living options and friends, relationships and community inclusion.

[Counselling Directory](#)

The Counselling Directory enables you to find a suitable counsellor, and they are dedicated to making the process as simple as possible, providing individuals in need with all of the information they require to make the most well informed decisions. Counselling Directory aims to be the leading service for providing counselling advice and information – connecting those in distress with the largest support network in the UK. They understand how important it is to find the right counsellor, the one that is exactly suited to your individual situation, have a look on their website for further information of the counselling services available in your local area, as a general rule counsellors with more experience will be accredited with the BACP.

There are many charities who offer support, advice and information to support our mental wellbeing some of these charities are:

[Mind](#)

Mind offer support and information including useful guides on support and services available, you can view these [here](#).

[Young Minds](#)

The charity Young Minds offer support and information for young people experiencing mental health challenges and their parents. They offer guides around support which can be found [here](#) as well as a beginner's guide to the NHS's Child and Adolescent Mental Health Services (CAMHS) for young people and parents, this guide can be viewed [here](#).

All about Living Well

Often people affected by Alström gain weight rapidly and in some, increased appetite (hyperphagia) is a factor. Considerations are also needed to find the right exercise programme takes into account the person's dual sensory loss . Help from a dietitian is recommended from an early age as possible for specific help and advice. In our experience, adults have been seen to benefit from modest restriction

of carbohydrate as well as calorie control and exercise. Diet and exercise are very important in the overall management of Alström and ASUK encourage healthy lifestyle choices by providing grants for exercise equipment or specific exercise programmes such as gym or swimming membership.

The NHS has advice and guidance on their 'Live Well' website. Follow the [link](#) here to find out more.

[2. All about Support from your Local Authority](#)

What are you entitled to?

ASUK have brought together some useful 'Hints and Tips' around the Care Act and how to receive a specialist assessment which should take into account your daily support needs. This can be downloaded [here](#)

Implementing the Care Act – The charity Sense also provide guidance on Deafblind assessments. Click [here](#) to read about how you can request and evidence your requirement for a specialist deafblind assessment.

Direct Payments and Personal Budgets

A direct payment is one of the ways you can receive money from your local council to help you pay for your support needs. Choosing to have a direct payment gives you more control over the services you use and who provides these.

Each local authority will have their own guidelines around Direct Payments, but we have gathered some general advice to follow:

The charity **Sense** offers a comprehensive guide around how to pay for your support:

<https://www.sense.org.uk/get-support/information-and-advice/paying-for-your-support/direct-payments/>

Carers UK, provide an easy-to-read guide including what you can and can't use Direct Payments for:

<https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/direct-payments>

Age UK provide detailed factsheets about Direct Payments and Personal Budgets:

https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs24_personal_budgets_and_direct_payments_in_social_care_fcs.pdf

The **NHS** provide useful information about Personal Budgets and Direct Payments:

<https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets/>

Carers Assessment

www.alstrom.org.uk

Reviewed October 2020CL

Generally when a person asks to be assessed for direct payments, a carers assessment will also be needed.

Carers UK offer practical support and information about these assessments: <https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/direct-payments>

Care and Support for Deafblind Children and Adults – DoH Policy Guidance

Useful information issued by the Department of Health, it provides policy guidance in relation to the Care Act 2014. To read the document in full click [here](#).

You have the right to ask for a Specialist Deafblind Care Assessment from social care if you have sight and hearing loss of any level. You do not need to be profoundly deaf or blind for this request to apply to your own circumstances.

Blue Badge; Disabled Parking Permits

The charity, Contact for families with disabled children offer comprehensive information about the blue badge scheme and how to apply. This is usually done through your local authority.

A blue badge costs up to £10 in England and £20 in Scotland, it is free for people residing in Wales. They usually last 3 years before you need to reapply.

New rules will come into force from the 30th August 2019 which will take into account hidden disabilities as well as many people now being able to automatically qualify if they meet specific rules. You can read the full information [here](#)

The Government have also announced a new online system which means applicants can complete the whole process online, hopefully making it easier and quicker to apply.

To apply online you will need a photo or scan of your:

- proof of identity (such as a birth certificate, passport or driving licence)
- proof of address (such as a Council Tax bill or government letter)
- proof of benefits (if you get any)

You will also need to provide a recent digital photo showing your head and shoulders.

You'll also need to know:

- your National Insurance number (if you have one)
- the details of your current Blue Badge (if you're reapplying)

You can find further information and apply online [here](#)

Challenging a decision

The local authorities don't always make the correct decisions, so just in case this happens we have provided some useful links about what to do next. But please don't forget your ASUK Family Support Worker is here to help and support you through this process.

Your local authority should have a complaints process in place to resolve your complaint. If you feel your complaint hasn't been resolved then your next step will be to make contact with the Social Care Ombudsman Service.

A useful link in challenging social care decisions around Adult Social Care can be found at **CASCAIDr** which stands for the Centre for Adults' Social Care – Advice, Information and Dispute Resolution

<https://www.cascaidr.org.uk/>

The Local Government and Social Care Ombudsman

This is a free service, which is often the final stage for complaints about councils, all adult social care providers (including care homes and home care agencies) and some other organisations providing local public services.

'We investigate complaints in a fair and independent way – we do not take sides.'
(quote from the IGO website)

<https://www.lgo.org.uk/>

3. All about your Rights & Benefits

Please also refer to the resource section 'All about Support from your Local Authority' which will also give guidance about your rights and benefits.

What are you entitled to?

ASUK have brought together some useful 'Hints and Tips' around the Care Act and how to receive a specialist assessment which should take into account your daily support needs. This can be downloaded [here](#)

Implementing the Care Act – The charity Sense also provide guidance on Deafblind assessments. Click [here](#) to read about how you can request and evidence your requirement for a specialist deafblind assessment.

Care and Support for Deafblind Children and Adults – DoH Policy Guidance – Useful information issued by the Department of Health as it provides policy guidance in relation to the Care Act 2014. To read the document in full click [here](#).

Blue Badge; Disabled Parking Permits

The charity, Contact for families with disabled children offer comprehensive information about the blue badge scheme and how to apply. This is usually done through your local authority.

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qualify if they meet specific rules. You can read the full information [here](#)
The Government have also announced a new online system which means applicants can complete the whole process online, hopefully making it easier and quicker to apply. You can find further information and apply online [here](#)

Working Families

Supports working parents and carers and their employers find a better balance between responsibilities at home and work. They offer a legal help-line to give parents and carers advice on employment rights, benefits and entitlements.

They also offer resources for parents of children who are affected by disabilities including knowing your rights, choosing childcare, entitlements and information about the 'Waving not Drowning Network' project. This project provides a helpline, newsletter, e-bulletin and occasional events and publications for parents of disabled children and carers of adults who want to combine paid work with their caring responsibilities.

You can find out more about these resources [here](#)

Renaissance Legal

Renaissance Legal specialise in working with families and carers of disabled and vulnerable individuals, helping them plan effectively for the future.

Office for Disability Issues (ODI)

Part of the Government Department for Work & Pensions. The ODI supports the development of policies to remove inequality between disabled and non-disabled people. Read the latest policy paper on disabled people's rights following the UK's first periodic review here: [Disabled people's rights: info following the UK's 1st periodic review](#)

Local Government and Social Care Ombudsman Service

This is a free service, which is often the final stage for complaints about councils, all adult social care providers (including care homes and home care agencies) and some other organisations providing local public services.

'We investigate complaints in a fair and independent way – we do not take sides.'
(quote from the IGO website)

4. All about Accessibility

Information and services should be in a format which is accessible for you and your needs.

The [RNIB](#) have useful resources on their website on many topics including accessibility. Click on the link [HERE](#) to find out more about accessible information, your rights, TV accessibility and talking ATM's.

RNIB also offer a reading service called '[Talking Books](#)'. This is a free service and the [RNIB Library](#) website offers all these reading services in one place. This includes Audio, Braille, Giant Print, Music – there is so much to access, borrow and enjoy. They also have a library helpline you can call on 0303 123 9999.

[Living Paintings](#) design, create and publish tactile and audio books for blind and partially sighted people. They call these Touch to See books. They publish titles suitable for anyone from pre-school to adult. The range is designed to provide education and life-long learning, enhance lifestyle and support leisure interests.

[RoboBraille](#) allows users in 4 easy steps to convert files into an accessible format, the converted file is then emailed to you.

[5. All about Education](#)

Educational Health Care Plans (EHCP)

[IPSEA \(Independent Parental Special Education Advice\)](#)

IPSEA is a registered charity offering free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND). They also provide training on the SEND legal framework to parents and carers, professionals and other organisations. They have some useful sample letters and information for families and professionals alike.

[Noddy Guide by David Wolfe](#) – relates to different aspects of EHCP

[SOS!SEN](#) The Independent Helpline for Special Education Needs. Offer a free, friendly, independent and confidential telephone helpline for parents and others looking for information and advice on Special Educational Needs (SEN).

Council for Disabled Children – A guide to what an EHCP should contain can be found [here](#)

[The School Run](#) – A website for primary-school parents who want to help their children with their education and make sure they stay healthy, have fun and get the best possible start in life.

[EHCP Journeys](#) – This site provides real-life examples of what it is like to go through the EHC process from the perspective of children, families and young people who are going, or have gone, through it. It also discusses ways for services to get feedback on their local delivery.

[Contact](#) are a charity for families with disabled children who provide support, guidance and information.

[6. All about Technology](#)

Technology has come a long way since tape recorders and mobile phones the size of bricks!

It can often be tricky to keep up to date with the most useful technology for your needs, so we have brought together some resources and useful organisations who can support you to be techno savvy!

Smartphones and tablets

Many of the mobile phones and tablets that are on the market today have in-built accessibility features such as voice activation, magnification and text-to-speech features. This means that you can make your device easier to use simply by adjusting the settings.

To keep up to date with emerging technologies in a fun blog for people with visual impairment [Cool Blind Tech](#) offers news, views and interviews on the best assistive technology.

[AppleVis](#) is a community-based website that offers support for people who are visually impaired and use Apple products.

The Perkins website [Paths to Technology](#) has been designed to assist educators, families and students with visual impairments and blindness who are in learning and to enable them to stay up to date in the ever-changing technology world.

There are so many different types of equipment, it is often good to go along to a support centre to try out different types in your local area. Here are a few examples of useful equipment and organisations who can support in your search.

Braille Devices

The Perkins website, [Paths to Technology](#) gives an overview of the different types of Braille devices such as; Braille display, smart display or a notetaker. It gives examples of each and tips to ensure the product you choose is right for you.

A braille display puts exactly what is on a computer, phone or tablet screen into braille on a device. It works alongside screen-readers such as Jaws, NVDA and Apple VoiceOver. Braille displays come with a Perkins style keyboard so users can either type using the computer keyboard or the braille display keyboard.

A braille note taker is like a laptop but instead of it having a screen, everything is displayed in braille and also has a built in screen-reader. There are two types of braille note-takers: a Perkins-style keyboard and one with a QWERTY style keyboard.

ClearReader, uses text-to-speech software to read printed documents out loud. For example, books, newspapers, magazines, letters and so much more. There are many different interpretations of these from various developers and companies.

[RNIB](#) offers technology support, including finding the right accessible technology and software for you. They also have an [RNIB shop](#) which offers various accessible products including the:

[RNIB PenFriend](#) is a labelling tool, it allows people to create personalised audio labels of things around the home. Stick a label on a product, record an audio clip of what it is and next time you need to know, scan the pen friend on the label and it reads the audio message out loud.

Apps

There are lots of apps on the market which are designed to help people with sight and/or hearing loss. Why not get in touch and tell us which apps are your favourites too:

Prizmo Go – an easy to use text-to-speech app

Seeing AI – narrates the world around you!

TextHear – real time text to speech translation

Spuble – turns spoken words into text

Aipoly Vision – identifies objects and colours

TapTapSee – photographs objects and reads aloud what they are

Visor – a magnifier and LED torch

Blind Square – GPS navigation

Boop Light Detector – tells you whether lights are on or off

Sound Alert – vibrates and flashes to alert you to household sounds like the doorbell, microwave, alarm clock etc.

NGT Lite – translates speech calls to text

Welcome – lets participating venues (shops, restaurants etc) know how best to help you

Voice activated technology

Through funding, in 2019/20 ASUK was able to provide youngsters with a Google mini-assist – which is one of a growing market for voice-activated devices, such as the Amazon Echo, or you may know her as Alexa! These are small internet-enabled speakers which will play music, search the internet, set alarms, tell you what the weather is like – and much more – all using voice activation. For people with dual sensory loss these products are extremely accessible and open up a whole new world of information.

[The RNIB article ‘How does the Amazon Echo help people with a visual impairment’](#) offers some insights into why the Amazon Echo is benefiting many people, particularly those with vision loss.

GPS assistants

Google Maps on your own smartphone is a great way to get to where you need to be. For example with some configuring, it might vibrate once to tell you to turn right and vibrate twice to tell you to turn left. There are other devices too you could try such as a personal GPS device, like the Trekker Breeze.

Home safety

It is important to think about how to stay safe in your home. Many options and devices are available online such as a vibrating or flashing smoke detector, doorbell and security alarm to give extra piece of mind.

[7. All about Activities](#)

Please find below resources and useful organisations who offer a range of activities. Please see the links below to find further information and please get in touch if you have any suggestions you would like to add:

[British Blind Sport](#)

The aim of this charity is to ensure people who are blind or visually impaired have opportunities to enjoy sport and recreational activities in the UK. They have recently launched 'Find a Guide Database' where anyone over the age of 18 can look for guide runners in their area. The guides are fully trained and DBS checked.

[Victa](#)

Provide support for children, young people and their families. They offer fun family activities throughout the year. You can view the 2017 list of activities [here](#) and the 2018 calendar of activities can be viewed [here](#)

[The Outlook Trust](#)

Provide adventure sports, activity week-end breaks and holidays for children who are blind or visually impaired.

[RNIB](#)

RNIB offer a range of activities and family events to get involved in. Including Actionnaires Clubs for 4 – 16 year olds. The clubs are provided throughout the UK and offer a range of activities including music, drumming, ten pin bowling, art,dance. swimming, athletics, basketball, goalball, judo, skiing, climbing, pizza making and attraction visits.

[The Calvert Trust](#)

Providing three activity centres two in the North and one in the South of England where anyone affected by a disability can explore a range of accessible adventure activities. ASUK have used the Calvert Trust centres a number of times and we have always been very impressed with the range of activities, accessible accommodation and welcoming staff, who believe it is what you can do that counts!

[Climbing Out](#)

Climbing out is based in the Lake District and offer fully funded activity breaks

[Over the Wall](#)

Providing fully funded activity breaks for disabled children.

[The Bendrigg Trust](#)

Offering a residential activity centre for people, of any age or ability in Cumbria.

[ACUK Centres](#)

Offering 5 venues across the Midlands, offering accessible accommodation and activities for all abilities.

[Aerobility](#)

Aerobility enables disabled and profoundly ill adults and children to share the magic which flying light aircraft brings – rediscovering smiles with the awakening experience of flight.

There are so many sports which are accessible for all, why don't you have a go at trying something new.

Please find below resources and useful organisations who offer a range of activities. Please see the links below to find further information and please get in touch if you have any suggestions you would like to add.

Accessible Sporting Organisations

British Blind Sport

The aim of this charity is to ensure people who are blind or visually impaired have opportunities to enjoy sport and recreational activities in the UK. They offer 'have a go' events, information and the links below will also help you find activities and running guides in your own area.

They have an 'Activity Finder' on their website where you can find accessible sporting activities in your local area. Head across to the [British Blind Sport Activity Finder](#) page to find out more.

If you are looking for a guide to support you with your running, British Blind Sport also offer a 'Find a Guide' resource where you can enter your postcode to find support near where you are. You can find more information [HERE](#)

British Paralympics Association

In need of inspiration - head across to The British Paralympic Association (BPA) website. This is where you will find all about the Paralympics and find out more about the Paralympics GB team [British Paralympic Association website](#).

Metro sport

Metro is a London based Sports and Social Club for blind and partially sighted people of all ages. Members include many of the UK's top international sports men and women, as well as those who are new to sport or who want to enjoy less competitive activities. For further information visit the [Metro blind sport website](#).

Disability Sport Wales

The Disability Sport Wales National Community Development Programme is a joint initiative between Sport Wales, the Federation of Disability Sport Wales and the 22 local authorities across Wales. The scheme is aimed at developing quality community based sporting and recreational opportunities for disabled people throughout Wales. For more details visit the [Disability sport wales website](#).

Archery

[British Blind Sport Archery](#)

Archery is accessible for all and there are many levels of archery, from being a recreational archer to being local, regional, national and international competitors. You can find out more on the Archery pages of the [British Blind Sport website](#).



Blind cricket

The main difference between standard cricket and blind cricket is the ball. A size three football is used in UK blind cricket to help the partially sighted players to see it. It's filled with ball bearings to allow the totally blind players to hear it.

[Blind Cricket England & Wales \(BCEW\)](#)

The BCEW have been working in partnership with British Blind Sport and the England and Wales Cricket Board since 2006 to deliver competitive cricket for those who are blind or partially sighted running national and international competitions. Find out more about blind cricket from youth development, the national league and

cup competitions to the England team. Head across to their website to find out more [BCEW website](#).

Cycling

By using specially adapted trikes or a tandem you can have a go at cycling which is accessible for you.

ASUK started a bike club in 2012 to fund adapted trikes and tandems to those who wanted to experience the joy of cycling in an accessible way. This was a great opportunity for families to cycle together and get fit in a fun way.

[Wheels for All](#) provide cycling events around the country and have centres to support individuals and families to cycle together. They can also help source suitable equipment. There are 50 centres across England and Wales; you can find your nearest centre [HERE](#)



Blind Football

Blind Football is a fast paced 5-a-side football played by athletes who have visual impairments using a ball with a noise-making device inside. It is played on a smaller pitch surrounded with a rebound wall. The sport is played with no throw-ins and no offside rule, which ensures non-stop action. Matches are played over two halves of 25 minutes each, plus 10 minutes for half-time. Blind football matches involve two teams with four outfield players and a goalkeeper. The outfield players are visually

impaired (VI) and wear eye-shades to ensure fairness. The goalkeeper may be fully or partially sighted.

The game was only introduced as a Paralympic event in 2004. There is more dribbling and short passing than in the mainstream sport, and crowds remain quiet during play to ensure that players can hear the ball, their team-mates and opposition players.

[British Blind Sport](#) runs the national 5-a-side football league for visually impaired players. It also hosts football development days throughout the country and an annual national schools tournament (for under 18's).

The FA run both an England Partially Sighted team and an England Blind team football. These teams compete at the European Championships and the World Cup.

You can find out more on the [Disability Football Directory](#)

<https://www.youtube.com/watch?v=-BBQaNVTYho>

You can watch footage of [David Beckham playing blind football](#) on the YouTube clip above.

Going to the football?

'[Level Playing Field](#)' work with those who provide live sporting events to ensure that sports fans with disabilities have a positive inclusive experience.

Bowls

The Scottish Association for Blind Bowlers - SABB

By the use of minor variations, blind and sighted people are able to play together as these variations do not infringe upon, or alter in any way the basic rules of the game. But they certainly do improve the standard of bowling.

[Visual Impaired Bowls England](#) is made up of 25 member clubs, and nearly 300 members.

[The Scottish Association for Blind Bowlers \(SABB\)](#) has 12 clubs in the association at the present time, and all are seeking new members and volunteers (bowling assistants). A full list of clubs and contacts will be found on the [Scottish Association of Blind Bowlers website](#).

Goalball

What is goalball?

Goalball is an exciting Paralympic, indoor, 3-a-side team sport, of attack and defend – with a unique twist! The sport was originally devised in 1946 to help rehabilitate

soldiers who had lost their sight during the war. It has been played throughout the world ever since, at the highest level, by people who are blind or partially sighted.

Goalball is a truly inclusive sport in that fully sighted players can also play domestically. This is because everybody is required to wear eye shades so that nobody can see. Players therefore have to rely entirely on their other senses.

The ball contains internal bells so players are able to track its movement by its sound, whilst the court is marked out with tactile lines so players can feel where they are. The idea of the game is quite simply to score goals by bowling the ball along the floor, past the opposing team.

Where can I play?

To find your nearest Goalball club, please visit the club teams section of the [Goalball UK website](#) or register your interest by calling 0114 223 5670 or emailing enquiries@goalballuk.com.

There are 3 levels of play within the Goalball UK National League (Novice, Intermediate & Elite) with competitions at all levels, throughout each season regionally and nationally.

Goalball UK also runs a number of individual entry tournaments that allow players to play with players from other clubs across the country.

For information about the domestic league and competitive playing opportunities, please contact Goalball UK on 0114 223 5670 or email enquiries@goalballuk.com.



Golf

[England & Wales blind golf](#) is a registered Charity, providing people with visual impairments the opportunity to participate and compete in the game of golf. Blind Golf is played strictly to the Royal & Ancient Rules of Golf with the exception that players are allowed to ground their club in a hazard.

The [Scottish Blind Golf Society](#) is a registered charity which provides competition and training in golf for registered blind and visually impaired people in Scotland, recognised as a governing body by The Royal & Ancient Golf Club of St Andrews.

Sailing

[East Anglian Sailing Trust](#) provides opportunities for sailing for people with visual impairments. Head across to their website to check out their latest events and sessions.

[Blind Sailing](#) is a Registered Charity, which aims is to help blind and partially sighted people sail at all levels. They organise regular training sessions, racing events and provide coaching and help to enable novices learn to sail.

[Sailability](#)

Sailability is the Royal Yachting Association (RYA) national programme enabling people with disabilities to try sailing and take part regularly. Sailing is open to anyone, no matter what age or disability. You don't need to be able-bodied, or even a strong swimmer. The network of approved Sailability sites will have boats and facilities to cater for everyone.

The Visually Impaired Sailing Association of Great Britain is a membership organisation run by blind and partially sighted sailing enthusiasts to help others enjoy the freedom of sailing. Get in touch with them on their website to find out more [VI-SA-GB](#)

[9. All about Travel and Independence](#)

Having a complex condition can sometimes make living independently and traveling a challenge but with the right support and planning this can be overcome. In this section we have brought together useful resources to support you to stay independent.

Many local authorities have their own specific information about independent living services in your local area. This is often a good place to start if you would like to know what services are available locally for you.

Please feel free to contact your Family Support worker who will also be able to offer support and guidance.

All about Independent Living

Disability Rights UK offer a range of factsheets about independent living. These can be viewed [here](#).

[Guide Dogs for the Blind](#) provide guide dogs which have been trained to help people affected by visual impairments to live independently. Guide dogs can benefit both children and adults, by increasing confidence, self-esteem, independence and mobility. Guide Dogs for the Blind also offer a range of services such as family events, family grants, mobility training, education and family support and offer a

sighted guide service for adults. They also offer CustomEye books which can be produced specifically to suit your child or young person.

All about Rail Travel

National Rail offer assistance to enable passengers with disabilities to travel. You can book to get help at any station for any train journey.

The train company can organise for someone to:

- meet you at the entrance or meeting point and accompany you to your train
- provide a ramp on and off your train if you need one
- meet you from your train and take you to your next train or the exit
- carry your bag (up to three items of luggage as per the National Conditions of Travel)

You can book help at short notice, but some companies may ask for up to 24 hours' notice. You only need to contact one train company and they will organise assistance for your whole journey. You can book assistance by phone or online with the company directly or centrally via the links and numbers below:

- disabledpersons-railcard.co.uk/travel-assistance/
- 0800 022 3720
- 0845 60 50 600 textphone/minicom

You won't have to pay extra if you can't buy your ticket before getting on the train due to your disability.

Disabled Rail Card and Discounts

You can get a 1/3 off with a Disabled Persons Railcard for travel on the National Rail network in Great Britain. If there is another adult travelling with you, they can also get 1/3 off their rail fare. You can use your rail card to get discounts any time of day and costs £20 per year. Further information can be found [here](#)

If you don't have a disabled rail card but are blind or visually impaired and need to travel with another person, you can get the following discounts:

- First Class or Standard – Anytime Single or Return – 34%
- First Class or Standard – Anytime Day Single – 34%
- First Class or Standard – Anytime Day Return – 50%

These discounts won't apply if you travel on your own.

Season Tickets for blind or visually impaired people

If you are blind or visually impaired, you can buy one adult Season ticket that enables a companion to travel with you on National Rail services only at no extra cost. It doesn't have to be the same person travelling with you on every journey.

You will need evidence of your visual impairment such as a document from a recognised institution such as Social Services, your Local Authority, The Royal National Institute for the Blind (RNIB) or St Dunstons when buying your ticket and making your journey.

These tickets can be bought from staffed National Rail station ticket offices.

Further information about these services can be found [here](#)

All about Bus and Underground Travel

If you are affected by a disability you can apply for a Freedom Pass which allows free travel across London on bus and underground and free bus journeys nationally. You can find more information, including eligibility and how to apply [HERE](#)

You will need to contact your local authority to check who issues bus passes for those who have disabilities. If you are eligible you will receive a bus pass for free travel anywhere in England.

Passes from councils in England can be used anywhere in England:

- at any time on a Saturday, Sunday or bank holiday
- from 9:30am to 11pm on any other day

All about Motors

The charity, Contact for Families with Disabled Children offer comprehensive information about the blue badge scheme and how to apply. This is usually done through your local authority.

A blue badge costs up to £10 in England and £20 in Scotland, it is free for people residing in Wales. They usually last 3 years before you need to reapply.

New rules will come into force from the 30th August 2019 which will take into account hidden disabilities as well as many people now being able to automatically qualify if they meet specific rules. You can read the full information [here](#)

The Government have also announced a new online system which means applicants can complete the whole process online, hopefully making it easier and quicker to apply.

To apply online you will need a photo or scan of your:

- proof of identity (such as a birth certificate, passport or driving licence)
- proof of address (such as a Council Tax bill or government letter)
- proof of benefits (if you get any)

You will also need to provide a recent digital photo showing your head and shoulders.

You'll also need to know:

- your National Insurance number (if you have one)
- the details of your current Blue Badge (if you're reapplying)

You can find further information and apply online [here](#)

Motability

The Motability Scheme enables people with disabilities to get mobile by exchanging their mobility allowance to lease a new car, scooter, powered wheelchair or Wheelchair Accessible Vehicle. You may be eligible to join the Scheme if you are in receipt of a higher rate mobility allowance.

All about Taxi's

If you live in London and are affected by a severe mobility impairments or a severe sight loss, you can apply for a Taxicard which will enable reduced taxi fares. Full information about the taxicard can be found [HERE](#)

If you travel with an assistance dog they must be allowed into the taxi or minicab with you, unless the driver has an exemption certificate. This can be issued if they've got a medical condition made worse by contact with dogs.

A driver with an exemption certificate will have a yellow 'Notice of Exemption' notice on their vehicle windscreen.

It's illegal to be charged extra to travel in a taxi or minicab with an assistance dog. Otherwise the driver could be fined up to £1,000.

The following types of dog can be taken with you in taxis or minicabs:

- guide dogs trained by the Guide Dogs organisation
- hearing dogs trained by Hearing Dogs
- assistance dogs trained by Dogs for the Disabled, Support Dogs or Canine Partners

Jetting off, high in the skies

It is essential that you let your airline know at least 48 before you travel if you will need assistance. Airlines and airports have different facilities for disabled people. Find out from your airport or airline if they have the facilities you need, for example a toilet with disabled access.

If you have a sensory, physical or learning disability which affects your mobility when using transport, at airports in the UK and EU you have the right to:

- help at specific arrival points, such as at terminal entrances, at transport interchanges and in car parks
- help to reach check-in
- help with registration at check-in
- help with moving through the airport, including to toilets if you need it

You'll also have the right to help because of your age or a temporary illness or injury – for example if you've broken your leg and it's in a cast.

You can travel with up to 2 items of mobility equipment free of charge if you're disabled. This will not count as part of your baggage allowance.

You cannot take your own wheelchair into the passenger cabin of a plane – it will be stored in the hold. Speak to your airline to find out what help they'll provide when boarding.

You should tell your airline, travel agent or tour operator as soon as possible if you're taking on a battery-powered wheelchair or mobility aid.

If you are travelling with a companion the airline you're flying with will do their best to make sure you sit next to each other, so long as you tell them at least 48 hours before departure.

You have the right to travel with your assistance dog. Make sure you contact the airport to check the rules that apply.

Across the water

You can get help if you're disabled and travelling on any of the following:

- a cruise ship that's leaving from a port within the UK
- a ferry that's leaving from or going to a port within the UK
- a local ferry service, for example by river bus

If you need to make specific arrangements for your journey (for example if you have certain accommodation or seating requirements), you should tell the cruise line, ferry service, travel agent or tour operator at least 48 hours before departure. You should also let the cruise line or ferry service know if you need to travel with a carer. On a ferry, your carer might be able to travel for free.

[10. All about coping with loss and grief](#)

Coping with loss and grief

Your first thoughts when you hear the words, loss and grief is the thought of the death of a loved one, which is often the most intense form of grief. But any loss can

cause grief, the loss of your job, divorce, health or even the loss of your dreams and aspirations. Whatever your loss, it is personal to you and there are ways you can cope and in time move on with your life in a positive way.

The [NHS](#) provide information about seeking help with grief after a bereavement or loss.

[Cruse](#) bereavement support offer support, information and advice to all ages when someone dies.

[The Good Grief Trust](#)

The Good Grief Trust exists to help all those suffering grief in the UK. They aim to find the bereaved, acknowledge their grief and provide reassurance and a hand of friendship and ongoing support. Their vision is to bring all bereavement services together around the country, to ensure that everyone receives the support they need.

[Child Bereavement UK](#) supports families when a child sadly dies or is dying and when a child is facing bereavement.

[Mind](#) offers information and support for those bereaved, including blogs of personal stories.

[Young Minds](#) support young people and their parents to cope with grief, including information on ways to work through your grief and showing personal real stories of how people have come to terms with their grief and moved on positively.

Short Films from the Alström Community

[Mum Julie talks about the challenges of fitness and health](#)

[Mary talks about some of the difficulties in deafblind services](#)

[Kerry reflects on her son becoming an adult](#)

[Joining up the global families through the Alstrom Patient Registry](#)

[Family Support Makes a Difference](#)

[Working Together, how do we find out more?](#)

[Join a Global Gathering](#)

[Dr Maffei and the Italian Job](#)

[Working with Wolfram and lessons for Alstrom](#)

[We have come a long way in 21 years](#)

Stay Fit, Stay Healthy, Stay Happy section

[Cooking up a storm!](#)

[Family Favourite, Keema recipe](#)

[Recreate Lady and the Tramp](#)

[Veggie chilli with herby rice](#)

[Aubergine chilli tray bake](#)

[Healthy Eating Top Tips](#)

[Let's get moving](#)

[My Road to Independence - Just do it!](#)

[My Google Assistance, is like a friend to me!](#)

[Tell everyone I can tell the time](#)

[I'm ready for any challenge!](#)

Growing-up section



What is T-KASH?

T-KASH (Transition-Knowledge And Skills in Health) are FREE resources created by young people (YP) from the Alström Syndrome UK Hear My Voice Youth Forum. They are for YP, families and professionals to help them understand transition in health settings.

The resources aim to:

- Draw attention to the knowledge and skills YP should be developing to manage their healthcare, while having the best life possible

- Prepare YP/families for identifying and coping with change at key points in their lives
- Supporting YP to plan for their future and cope with their eventual transfer/settling into adult services

Contact Information:

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