

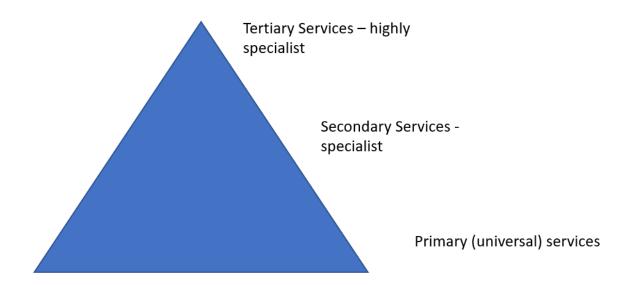
# Pinpoint's Health Guide

#### Section 1 How health services work

### How health is organised\*

\*the system is changing and we will shortly update this section to reflect the new Integrated Care System

The NHS provides services that everyone in the population can access. Some children and young people's health needs means that their needs can be met from the services available to everyone – we call these 'primary' or 'universal' services, and this might include GPs and Accident and Emergency departments. Some children and young people will have more complex needs and may need more specialist services – 'secondary services. A small number of children will need highly specialised 'tertiary' services. Whatever your child's needs there will be a service that can meet them.



Some children will be born with complex health needs and those services will have been part of the support offered from birth – some examples might be sight loss, physical disabilities, genetic conditions or heart problems, for example. Some children will have a sudden change of health and then specialist services will kick in to meet those needs – a life changing accident or a life limiting illness for example. Most children may have needs that come and go or emerge with time. These children will often start with primary services like the GP and then, if necessary, will be referred on to see specialists. Sometime the care becomes part of a lifelong health need and somethings with treatment it is no longer a need. Whatever your child's needs there is help and support.

### **How Health is organised in Cambridgeshire**

<u>Cambridgeshire & Peterborough Clinical Commissioning Group (CCG)</u> is responsible for planning, organising and buying NHS funded healthcare for people living in the Cambridgeshire and Peterborough area who are registered with a GP practice.

Local GP practices are organised in clusters called "Local Commissioning Groups" to commission (buy) health services for their local population.

<u>Cambridgeshire Community Services</u> provide universal services, such as health visitors, child health services and school nursing, targeted services such as Children's Physiotherapy, Occupational Therapy, Speech and Language Therapy through to specialist care in hospitals and in the community for children and young people with the most complex needs. Services are offered to children from birth up to 19 years of age.

### Become an 'Expert Parent in Health'

Pinpoint offers the Expert Parent Training Programme designed by the Council for Disabled Children. The Expert Parent Programme began in 2014, supported by research led by Every Disabled Child Matters campaign which found that parents and carers of disabled children faced numerous barriers in accessing health services and struggled to navigate the health system.

Developed with funding support from the Department of Health (now called Department of Health and Care), from NHS England, and Health Education England, the Expert Parent Programme drew on evidence of the positive impact of parent-led training and empowers parents of disabled children and young people to become more confident and resilient when engaging with health services, and the other services that they come across.

The course is free to parent carers and can be booked via Pinpoint's website.

Acronyms – what do those letters stand for?!

Do you ever feel lost at the volume of acronyms in the NHS? The NHS confederation has a useful acronym buster for NHS terms <a href="here.">here.</a>

# Commissioning and decision making for health services in Cambridgeshire

The responsibility for organising local health services is quite complex.

<u>Cambridgeshire and Peterborough Clinical Commissioning Group (CCG)</u> is the local NHS organisation responsible for commissioning many local health services for residents registered with a GP.

Cambridgeshire County Council and Peterborough City Council also jointly manage some local services such as Health Visiting and School Nursing and some specialist services such as children's head injury rehabilitation are organised locally and nationally by NHS England.

We know it is very confusing, so if you have a child with a disability or special educational needs and you are unsure of who to contact or how to be referred for a particular service, you can discuss this with your GP.

### Decision making in health in Cambridgeshire

The Designated Clinical Officer supports Cambridgeshire and Peterborough Clinical Commissioning Group to meet its statutory responsibilities for children and young people with special educational needs and disabilities, and agrees the health services within an Education, Health and Care plan.

The Designated Clinical Officer in Cambridgeshire and Peterborough is a qualified and experienced nurse, who has extensive experience and expertise in working with children and young people with a range of disabilities and health needs.

### The Designated Clinical Officer:

is a point of contact for local partners, when notifying parents and the local authority about children and young people they believe have or may have SEN or a disability?

offers advice on SEN or disabilities

provides health advice to local authorities, schools and colleges regarding children and young people with SEN or Disabilities

provides a contact for CCGs or health providers so that appropriate notification can be given to the local authority of children under 5 years who they think may have SEN or a disability

agrees the health services within an Education, Health and Care (EHC) plan

If you have any questions, please contact the Designated Clinical Officer for SEND, Siobhan Weaver, on 01733 847 326 or email capccg.send@nhs.net

You can also look at our **Decision Making** webpage for more information

### **Continuing Care Funding**

The Clinical Commissioning Group fund health care for children and young people through Continuing Care. These exceptional and individual funding requests are usually for medications or treatments which are not routinely provided through other health services that they or NHS England organises.

Continuing care requests need to be supported by clinical reports and recommendations from professionals involved with your child. However, your GP should be able to help you with this.

# Section 2: Getting your voice heard in Cambridgeshire

### Parent Carer Voice and Representation in health

### Pinpoint, Cambridgeshire's Parent Carer Forum

Pinpoint is the Parent Carer Forum for Cambridgeshire. We support parent carers of children and young people aged 0 -25 years with additional needs or disabilities. As a parent carer forum, we enable the Local Authority to fulfil its statutory requirement to listen, engage and work together with parent carers for the benefit of children with Special Educational Needs and Disabilities (SEND) and their families.

### Pinpoint:

- Provides information and signposts parents and carers to the services best suited to help them with their child's needs.
- Engages and empowers parent carers by running free events, workshops and training, including an annual conference, and helps them ask for the services their children need.
- Works with statutory services as both a partner and critical friend; they both fund and provide support and services and Pinpoint ensures parents' voices are heard and that parents help to shape services.

### Health

We work with health colleagues to ensure that parent carers views and needs are heard and understood. We do this through representation on the following health boards and working groups:

- Children's Health and Wellbeing Board
- NHS Covid Recovery Board
- Joint SEND Executive Board
- Cambridgeshire SEND Partnership Board
- EHCP Review Group
- Carers Board
- The Learning Disability Board
- Co-production All-Age Mental Health Working Group
- Joint All -Age Autism Strategy Board

Pinpoint also represent Cambridgeshire Parent Carers on

- Children and Young People's Palliative Care Eastern Region
- The Neuro-Development Disorders Network Board for the Eastern Region

We convene a termly meeting with commissioners, Partners in Commissioning, including health, to raise issues and proactively consider how services can best meet the needs of Cambridgeshire's children and young people.

We routinely co-produce policies, advice and guidance to ensure the needs of parent carers, and their children, are met. We have co-<u>produced</u> the Local Offer, including the section on health. You can find details of how to '<u>join in'</u> here.

Pinpoint offers support and signposting to services for parent carers through regular Tii Hub drops ins. They offer a wide range of workshops and information sessions, most of which are online, and are free to attend. They can be booked via <u>Pinpoint's website</u>.

### Patient and Service User Voice - Cambridgeshire's Healthwatch

Healthwatch are the independent champion for people who use health and social care services. They work to make sure that those running services, put people at the heart of care. Healthwatch's sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf. They work to get services right for the future.

Healthwatch represent all health service users, not just those with SEND. They chair the Learning Disability Partnership. They are invited to Pinpoint's Partners in Commissioning termly meetings to meet with service commissioners.

You can let them know your thoughts about health services by contacting them through

### **Compliments, Comments and Complaints**

their website.

If you or your relatives are unhappy about any aspect of your care or the services you have received, please speak to a member of staff in the first instance.

Problems can often be sorted out on the spot. If you feel able to talk to those concerned, you can give them the opportunity to put things right.

If you don't want to speak to a member of staff or you still feel dissatisfied and your issues have not been resolved, you can either contact our <u>Patient Advice and Liaison Service</u> (PALS) or you can choose to make a formal complaint.

We view complaints positively, using them as an opportunity to improve services.

### **Exceptional Circumstances – Changes to complaint response timeline**

As a result of the covid 19 pandemic we are currently operating with revised complaint response timelines as described under business continuity in our Patient Experience policy.

Therefore, the following timeline will apply until further notice. We will review this position on 31/7/2021.

Current timelines are 35 days for complaints involving one service and up to 5 issues and 40 days for all others.

The Resolution and Complaints team will inform you of your complaint timeline within 3 working days of receiving your complaint.

Our complaints team can be contacted as follows:

FREEPOST: RTGA-CTLG-SCKH
The Resolution and Complaints Manager
Complaints Team
Units 7/8, Meadow Park
Meadow Lane
St Ives
Cambs, PE27 4LG

Tel: 0300 555 5544

Email: ccs.complaints@nhs.net

The Resolution and Complaints Manager will work with you to resolve your complaint. If you have written or emailed, they may speak to you to help understand your concerns more fully and to work out a way these can be resolved.

Your complaint will be investigated and you will receive a full report explaining what has occurred and what action has been taken. The timescales for receiving this will also be agreed with you and we will keep you informed throughout the process.

If you wish to view the full Complaints Policy for Cambridgeshire Community Services NHS Trust then please <u>click here</u> for the Trust Policy page and search for document number DN060.

What happens if I am still not satisfied?

We will do everything we can to resolve your complaint, including arranging meetings with staff involved and seeking independent medical advice. We also have trained independent conciliators who can work with all parties to work out more complex issues.

In the rare circumstances where you are still dissatisfied with the response, you can contact the **Parliamentary and Health Service Ombudsman** .

The Parliamentary and Health Service Ombudsman Millbank Tower Millbank London SW1P 4QP

Telephone: 0345 015 4033

email: phso.enquiries@ombudsman.org.uk

www.ombudsman.org.uk

The Ombudsman will usually expect a complaint to have followed our complaints procedure before considering it.

If you would like to share a positive experience about your care, or just make a comment on our services, we would be delighted to receive these and share them with the staff involved and, through our staff newsletter, with a wider audience.

You can send your compliments to:

Cambridgeshire, Peterborough, Norfolk and Suffolk locality:

Freepost: RTGA-CTLG-SCKH
PALS & Patient Experience Team
Units 7/8, Meadow Park
Meadow Lane
St Ives
Cambs, PE27 4LG

Click here for our <u>Patient Information Leaflet</u> - Cambridgeshire, Peterborough, Norfolk and Suffolk

**Luton locality:** 

**Freepost:** CCS LUT PATIENT EXPERIENCE

# **Section 3: Getting Help**

### Who do I ask for help?

If you have concerns or questions about your child's health, talk to your doctor, health visitor, school nurse for medical services or your dentist for dental services. They can help with a wide range of health issues and any concerns you might have about your child's development. They can also refer you to specialist health services depending on your child's needs. This might include <a href="https://physiotherapy.com/physiotherapy">physiotherapy</a>, <a href="https://occupational.therapy">occupational.therapy</a>, <a href="https://occupational.therapy">speech and language</a> <a href="https://occupational.therapy">therapy</a>, <a href="https://occupational.therapy">child and adolescent mental health services</a>, <a href="https://wheelchair.services">wheelchair.services</a>, <a href="https://child.com/physiotherapy">child and adolescent mental health services</a>, <a href="https://wheelchair.services">wheelchair.services</a>, <a href="https://child.com/physiotherapy">child and adolescent mental health services</a>, <a href="https://wheelchair.services">wheelchair.services</a>, <a href="https://child.com/physiotherapy">child and adolescent mental health services</a>, <a href="https://wheelchair.services">wheelchair.services</a>, <a href="https://wheelchair.services">community nursing</a> and the <a href="https://www.services">special dental service</a>.

If your child is supported by a number of professionals from health, education and social care they will work together in a multi-agency team to make sure support is co-ordinated and appropriate.

You can find information about your local doctor, hospital and dentist on the NHS website.

### Services by age group

### 0 -16 years

Children aged 0-16 will access children's services, usually through their GP, health visitor or paediatrician, and usually led by their parent carer or guardian. You will find details about Cambridgeshire's Children and Young Peoples' Health Services here.

#### 14 years plus

If you are aged 14 years or over, you and have a learning disability you are entitled to a free annual health check from your GP (link to section below)

# 16 years plus

If you are aged 16+ years old and up, then you will start to access some adults' services and take the lead in making decisions about your health.

If you are under 18 with a learning disability, then you will still be able to access children's services but will also have more of a say about your care. You are also entitled to an annual health check (see below).

# 18 years plus

If you are 18 + you will access adult health services.

#### The changing role of the parent carer or guardian

A parent carer or guardians role changes as children take legal responsibility for their health but many will still need help and support to do so. The Preparation for <u>Adulthood Parent's Guide</u> has lots of information to help support the changes roles and responsibilities as well as wider information useful for those who have a child aged 14 years plus.

### The legal rights of children, young people and adults

<u>Get Your Rights</u> is a new interactive website which helps to explain to children and young people their rights when using the NHS. The <u>Citizen's Advice Bureau</u> also provide wideranging advice and support.

### Section 4: Education Health Assessment and Education Health and

# **Care Plans**

Children with health needs may need a Healthcare Plan. This would be appropriate where health alone is the need, rather than health with educational and social care needs. The Department for Education's Statutory <u>Guidance Supporting pupils with medical conditions at school</u> (2014 and 2017)

#### sets out that:

- Pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education.
- Governing bodies must ensure that arrangements are in place in schools to support pupils at school with medical conditions.
- Governing bodies should ensure that school leaders consult health and social care professionals, pupils and parents to ensure that the needs of children with medical conditions are properly understood and effectively supported.

For those children with complex needs that cannot be met by the support put in place by their school or college, an EHC needs assessment may be required. You can find out more here (link to section of website).

# **Section 5: Services Directory**

# Annual Health Checks for people with a learning disability

People with a learning disability often have poorer physical and mental health than other people. This does not need to be the case. Annual health checks are for adults and young people aged 14 or over with a learning disability. You can ask your GP for your young person to be added to their Learning Disability Register. They will then be invited for an annual Learning Disability Health Check. Watch a short film about the health checks, find out what to expect and how to make sure your young person gets one.

# **Attention Deficit Hyperactivity Disorder**

ADHD is a medical diagnosis that can only be made by a suitably qualified medical professional.

In Cambridgeshire this is provided for the NHS by the Community Paediatric Team for primary

school-aged children and the child psychiatrist (CAMH) for secondary school age. Referrals are through professionals working with the child: the school, a paediatrician or GP.

For adult (18 years and older) referrals you can contact <u>Cambridgeshire's NHS service</u>.

### Audiology

The Community Paediatric Audiology Service provides hearing assessment and advice for children for whom there is concern about hearing. They can assess children aged 9 months old to 16 years old and will require a referral from your child's GP, Health Visitor, School, Paediatrician or Speech Therapist. For those who are 16 years or older, the GP can assess and refer to services as needed.

### **Autism Spectrum Disorder and Social Communication Difficulties**

Autism is a lifelong developmental disability which affects how people communicate and interact with the world. Cambridgeshire and Peterborough are developing an All-Age Autism Strategy. Autism is diagnosis that can only be made by a suitably qualified medical professional. Children who do not have a diagnosis of autism may be diagnosed as having Social Communication Difficulties. Cambridgeshire NHS have produced a Guide.

In Cambridgeshire, this service is provided through the NHS by the Community Paediatrician or Clinical Psychologist for preschool <u>and primary school-aged children 0 -11 years</u> and the Child psychiatrist/psychologist (CAMH) for secondary school age, 11- 18 years. Young people over the age of 18 will be referred by their GP to adults' mental health services and Cambridge Lifespan Autism Spectrum Service (CLASS)

### **Behaviour concerns**

Help with managing behaviour is one of the top topic's parents tell us they want to have better information on, and support with. There are lots of things to try that can make a really big difference – some are quick wins, and some take longer to work. There is no magic wand that fixes things but by trying different approaches you may make things easier for your child and for you / your family.

It starts with trying to work out what happens and when, before then working out what things make the behaviour disappear, more manageable or worse. Some things work all the time and sometimes you'll need to adapt as your child changes.

Talk to your child's nursery or school— they will be able to help with advice and can access additional support from education and health services if needed. Many schools work closely with Family Workers who can offer one to one support and advice. They can help you to explore what is working and what else you might try. If you have a health visitor or paediatrician, they will be able to offer advice and support too.

Early Help is a free Cambridgehsire County Council service that helps families who need a bit of extra support. You might be worried about your child's behaviour or development. Or you and your family might experience some changes or difficulties that you can't manage by yourself. Whatever you are worried about, Early Help can support you and your family so that small problems do not become big problems.

- The professionals who know you will assess the needs of your family using an Early Help Assessment. This will help you to get you support as quickly as possible.
- It is a voluntary process. You choose whether to be involved and can withdraw from the process at any time. Sometimes, children and young people can make their own decisions about whether they need an Early Help Assessment, and who they want to support them.

If you think you and your family might benefit from some support, you should ask a professional who you know. This could be your doctor, or a teacher at your child's school. They can tell you more about Early Help.

You can also contact the Early Help Hub: <a href="mailto:early.helphub@cambridgeshire.gov.uk">early.helphub@cambridgeshire.gov.uk</a> or call: <a href="mailto:01480.376.666">01480.376.666</a> (office hours). If you don't know who to ask for help.

Sometimes a professional may approach you and ask whether you would like to talk about Early Help and how it could help your family.

<u>Pinpoint run free workshops</u> for parent carers each month in term time, many of which feature managing behaviour:

Cambridgeshire's Child and Family Centres run free courses too.

Cambridgeshire County council also offer a range of courses for parent carers:

# Chewing, biting and issues with mouths

Some children may seek extra sensory input using their mouths – biting and chewing items can be part of this. Some may have weak muscles and struggle to bite and chew. Some children have a desire to try to eat things we would not think of as food e.g., soil, chalk. – we call this Pica. If your child has issues like these talk to your GP who can decide on the right type of help. Those of 18 should also talk with their GP if there is an issue.

# **Community Nursing**

For those under 16 years of age, the <u>children's community nursing</u> team offer specialist nursing support to families who have children or young people with nursing or medical needs in the home or other community setting e.g. a school.

The team also has specialist nurses and nursery nurses who have experience and knowledge in the following areas:

- Acute care
- Asthma
- Cystic Fibrosis
- Complex needs
- Enteral feeding
- HIV
- Oncology
- Palliative care
- Tuberculosis.

The team endeavour to care for children at home to reduce hospital admissions and minimise the length of stay whenever it is safe to do so.

The service operates seven days a week, Monday to Friday, 8am to 6pm. Weekends and bank holidays, 9am to 5pm.

Tel: 0333 4050079

For those who are 16 years or older the GP should be able to refer you to <a href="the-the-those who are 16">the District</a> <a href="https://www.nushib.com/nushib.

### **Community Paediatricians**

The <u>Community Paediatric Service</u> assesses and manages children (0-18 years) who live in Cambridgeshire who have significant problems with development and or disability. The service provides a wide range of medical advice, assessment, diagnosis, treatment and support services in the following areas:

- Children with developmental concerns including potential Autistic Spectrum Condition (ASC) and Attention Deficit Hyperactivity Disorder (ADHD) diagnoses
- Children in special schools requiring medication or other treatments during the day
- Medical advice for Education Health Care Plans
- Safeguarding children, child protection and children in need

#### Benefits from this service include:

- Maximising the health of children
- Medical problems are identified and addressed at the earliest opportunity
- Children are supported to remain in education
- Children's safety and wellbeing is protected
- Children, young people and their families are enabled to lead independent lives

referrals to the service are made by the GP

# **Continence Support**

Some children struggle to become dry and clean – toilet training can be a struggle, or a new pattern of wetting and soiling happens. You can talk to your GP, health visitor or paediatrician and ask for help and advice. Cambridgehsire has a paediatric continence service for children aged 4-19 and how to make a referral can be found <a href="here">here.</a> For those who are older there is an adult service.

### Dentistry

The NHS will provide any clinically necessary treatment needed to keep your mouth, teeth and gums healthy and free of pain. You can find your local dentist here.

You're entitled to free dental care if you are:

aged under 18, or under 19 and in qualifying full-time education

pregnant or have had a baby in the previous 12 months

staying in an NHS hospital and your treatment is carried out by the hospital dentist

an NHS hospital dental service outpatient – but you may have to pay for your dentures or bridges

You're also entitled if you or your partner – including civil partner – receive, or you're under the age of 20 and the dependant of someone receiving:

**Income Support** 

Income-related Employment and Support Allowance

Income-based Jobseeker's Allowance

Pension Credit Guarantee Credit

Universal Credit and meet the criteria

If you're entitled to or named on:

a valid NHS tax credit exemption certificate – if you do not have a certificate, you can show your award notice; you qualify if you get Child Tax Credits, Working Tax Credits with a disability element (or both), and have an income for tax credit purposes of £15,276 or less

a valid HC2 certificate

People named on an NHS certificate for partial help with health costs (HC3) may also get help.

Some children and young people's health needs mean that they struggle to access ordinary dental services. The <u>special care dental service</u>. provides a comprehensive range of activities to improve the oral health of children and adults who have a physical, sensory, intellectual mental, medical, emotional or social impairment or disability, which makes routine care in general dental practice unsuitable or impractical for their needs.

Patients are only accepted by our special care dental service on referral from General Dental Practitioners. Referrals are subject to eligibility criteria, which can be found here. If you have any queries, please call us on 0300 555 6667 and press option 2.

# Disability Living Allowance - see welfare benefits on Pinpoint's website

### Drugs, alcohol and substance abuse

Support is still available for anyone with a drink or drug problem. If you need help your GP is a good place to start. They can discuss your problems with you and get you into treatment. You can call your GP practice as usual for an appointment. The <a href="NHS website">NHS website</a> has lots of information that can help. There is also help available through the organisations below

#### Telephone helplines:

- Drinkline provides free advice and support, on <u>0300 123 1110</u>
- FRANK provides free information and advice on drugs, and information on where to get help, on <u>0300 123 6600</u>
- the National Society for the Prevention of Cruelty to Children (NSPCC) helpline, if there are worries about a child or young person, on 0808 800 5000
- The National Association for Children of Alcoholics (Nacoa), on <u>0800 358 3456</u>
- Childline provides advice for anyone under 19, on 0800 1111

#### Websites:

• One You Drink Less, which offers advice on cutting back on alcohol

- FRANK, which offers information and advice on drugs and where to get help
- <u>Down Your Drink</u>, which provides interactive web-based support to help people to drink more safely
- <u>Nacoa</u>, which provides information, advice and support for anyone affected by a parent's drinking
- Childline online access to mutual support including:
- SMART Recovery
- Alcoholics Anonymous (AA)
- Narcotics Anonymous (NA)
- Cocaine Anonymous (CA)

# **Dyspraxia or Developmental Co-ordination Disorder**

Developmental co-ordination disorder (DCD), also known as dyspraxia, is a condition affecting physical co-ordination. It causes a child to perform less well than expected in daily activities for their age and appear to move clumsily.

DCD is thought to be around 3 or 4 times more common in boys than girls, and the condition sometimes runs in families.

If you're concerned about your child's health or development, talk to a GP or health visitor, or speak to a nurse, doctor or special educational needs co-ordinator (SENCO) at your child's school. If necessary, they can refer your child to a community paediatrician, who will assess them and try to identify any developmental problems. If you are older than 16 years talk to your GP.

### **Eating Issues**

Some children may have difficulties with feeding from birth - difficulties taking milk, allergies or reflux, for example. These may be a result of physical needs and most can be addressed with changes to milk, advice and minor medical procedures. Some issues may be longer term, and some may be life-long: some may require medical procedures or ongoing medical support. Some children do not develop eating issues until they are older. For some, moving onto solid foods is when it shows and again it often a physical need that is seen. As children grow, they take more control of their eating and some disorders are seen during this stage - this could include what children choose to eat, how they choose to eat and when they choose not to eat. Sometimes the eating is part of a wider need that you can see through food and sometimes its only food related. It can be a physical need or an emotional mental health need.

If you have concerns then talk with your child's GP, health visitor or paediatrician. Young people can seek their own referrals over the age of 17 or 18 through their GP. Those who

need specialist services may be referred to Dietetics, Nutrition, and to services for specialist equipment and other related support.

If your child's eating and drinking suddenly stops or become very restricted or becomes unwell, please seek immediately medical advice from the GP or NHS 111 to ensure they are safe and well.

#### Gender

If your child is experiencing discomfort or uncertainty about their gender identity, and it's causing distress, it's important they talk to an adult you can trust.

Options include parents, who may be much more supportive than you expect. Schools and colleges are now much more aware of trans and gender identity issues, are keen to support young people and have a duty to do so.

If your child doesn't feel able to talk to someone they already know, there are several charities and local gender support groups they can talk to. Many have trained counsellors they can speak to in confidence. You can find a list of charities and support groups here.

There is NHS help available for teenagers who need support around gender.

If you have strong and continuing feelings of identifying as a gender that is not the one you were assigned at birth, and are distressed about this, there are various options available. These include talking therapy and hormone treatment and, after 18 years of age, surgery if appropriate.

Your GP, other health professional, school, or a gender support group may refer you to the <u>Gender Identity Development Service (GIDS)</u> at the Tavistock and Portman NHS Foundation Trust.

This NHS service specialises in helping young people up to the age of 18 with gender identity issues. It takes referrals from anywhere in England. Its principal clinics are in London and Leeds.

#### Genetics

Genetic testing – sometimes called genomic testing – finds changes in genes that can cause health problems. It's mainly used to diagnose rare and inherited health conditions and some cancers.

You may be offered a genetic test because:

your doctor thinks you might have a health condition caused by a change to 1 or more of your genes someone in your family has a health condition that's caused by changes to genes some of your close relatives have had a particular type of cancer that could be inherited you or your partner have a health condition that could be passed on to your children

If you have any questions, talk to your doctor about having a genetic test.

<u>The Cambridge Rare Disease Network</u> supports families, children and young people. There is also a Cambridge Babies and Children with Downs Syndrome Group.

# **Global Developmental Delay**

Global Developmental delay is a name ('diagnosis') given by doctors when a child has not reached two or more of their developmental milestones at an expected age. The term 'delay' is misleading as it is uncommon for children to simply 'catch up'. Most children with GDD continue to have difficulties as they get older. Children are often diagnosed with learning difficulties/disabilities when they start school. Please make sure you speak to the SENCO at your child's school if you have concerns about your child's support/ progress. If you continue to have concerns you may ask your GP for more advice and they make refer you to a community paediatrician.

#### **Health Checks**

Annual Health Checks for people with a learning disability People with a learning disability often have poorer physical and mental health than other people. This does not need to be the case. Annual health checks are for adults and young people aged 14 or over with a learning disability. You can ask your GP for your young person to be added to their Learning Disability Register. They will then be invited for an annual Learning Disability Health Check. Watch a short film about the health checks, - find out what to expect and how to make sure your young person gets one.

# **Healthy Lifestyles**

<u>Everyone Health</u> has partnered with Cambridgeshire County Council to provide healthy lifestyle support to people living in Cambridgeshire. It is a free service for Cambridgeshire residents who are looking to make changes to their lifestyle. Whether you want help to quit smoking, lead a more active lifestyle, lose some weight, or simply take advantage of the NHS Health Checks on offer, Everyone Health – alongside Cambridgeshire County Council – can help you.

### **Hospitals**

There are a number of hospitals across our region, and beyond, some offering universal services and other with specialist services and known as being leaders in certain medical fields, like heart surgery or children's plastic surgery. When you are referred to services that are in a hospital you will be sent to right clinic in the right hospital for your child's needs. This may be your nearest hospital, but it can sometimes mean you need to travel further to the hospital offering what is needed.

We have three hospitals in Cambridgeshire:

Addenbrookes in Cambridge

Hinchingbrooke in Huntingdon

The Rosie (Maternity) in Cambridge

Royal Papworth (Heart) in Cambridge

You may live nearer hospitals outside of Cambridgeshire and be referred there:

Peterborough City in Peterborough

The Queen Elizabeth in Kings Lynn

Or be referred to a hospital with a specialist hospital or unit such as

Great Ormond Street which is one of 30+ children's hospitals in the UK.

### **Hospital Health Passports**

Hospital passports can also help with visits and hospital stays but making it easy for the adults who will meet your child during their visit understand their special educational needs and disabilities at a glance



Pinpoint, Cambridgeshire's Parent Carer Forum, worked with parents and Addenbrooke's Hospital to create an Additional Needs passport for children and young people attending the hospital. There are child and adult versions. Download the <u>Addenbroooke's Hospital passport</u>

There is also a general healthcare passport template. Use it at hospitals, clinic visits or GP appointments. Or keep a spare for holidays or one in the car glovebox in case of emergency. <u>Download a general Healthcare Passport</u>

Mencap and NHS England created a short emergency version for the COVID-19 outbreak to enable healthcare professionals to know immediately about your child's needs. Download the <u>2020 COVID-19 'Grab and Go' Healthcare Passport</u>.

# **Hospital Learning Disability Nursers / Advisors**

Most of our children will be treated locally and the local hospital's <u>Learning Disability Nurse / Advisor</u> will be able to offer help and answer questions. Learning Disability Nurses understand the needs of people who have a learning disability and/or autism, and also understands how hospitals work. Nurses/Advisors can work with the hospital to help you get the care, treatment and tests you need. <u>Learning Disability Nurse Easy read document</u> with further information and contact details.

### Hospitals - getting more help

If you need help and advice about your treatment in hospital, contact the Patient Advice and Liaison Service (PALS).

Most hospitals have their own PALS contact you can approach.

Cambridgeshire's PALS have their own website

#### Housing and health

If your child's heath needs mean that your home needs to be adapted, then there is help available.

Your local council offers a service that assesses your home and recommends changes to help. Having a <a href="https://example.com/home-assessment">home assessment</a> is free.

Your Local District Council has grants to help pay for adaptions for disabled people.

**Cambridge City Council** 

East Cambridgeshire District Council

South Cambridgeshire District Council

**Huntingdonshire District Council** 

**Fenland District Council** 

These changes can be small or big and include:

fitting a stairlift or a banister on the stairs

adding a bath lift, walk-in shower or a rail you hold to pull yourself out of the bath (grab rail) widening doorways

lowering kitchen worktops

putting in an outdoor ramp or step rail

security, such as outside lights and intercom systems

The assessment might also recommend household equipment and gadgets to make life easier.

If you, or someone you know, needs help to do everyday tasks or you're worried about falling, ask social services for a home assessment.

You can call your local council or do it online.

Home assessment - how to apply

If you are in social housing and changing health needs mean you need extra space for equipment don't forget to tell your local district council housing team as they may help with finding a home with more space for the adaptions your family needs or which better suits your child's health needs.

If your housing association home conditions make a health condition worse, you should also alert your housing association and local district council team and ask for help to address the issue.

You may be entitled to welfare benefits to help towards the additional housing costs associated with your child's needs.

# Life-limiting needs and Palliative Care

If you have been told that you or your child may not get better, you might also have heard about palliative care. Palliative care is for people living with a terminal illness where a cure is no longer possible. It's not just for people diagnosed with terminal cancer, but any terminal condition. It's also for people who have a complex illness and need their symptoms controlled. Although these people usually have an advanced, progressive condition, this isn't always the case.

Palliative care aims to treat or manage pain and other physical symptoms. It will also help with any psychological, social or spiritual needs. Treatment will involve medicines, therapies, and any other support that specialist teams believe will help their patients. It includes caring for people who are nearing the end of life. This is called end of life care.

The goal is to help you, and everyone affected by your diagnosis to achieve the best quality of life. You might receive palliative care alongside particular treatments, therapies and medicines, such as chemotherapy or radiotherapy.

Marie Curie have a suite of Easy Read booklets about palliative care.

East Anglia's Children's Hospices (EACH) supports families and cares for children and young people, 0-18 years, with life-threatening conditions across Cambridgeshire, Norfolk, Suffolk, and North, Mid and West Essex. Their family centred approach includes specialist nursing care, symptom management support, short breaks, wellbeing activities, therapies and counselling; all meeting the individual needs of the child, young person and whole family.

Their hospices aren't just about end-of-life care; they're often very happy and fun places, where young people can live life to their full potential. They are places where families feel safe, at home and where they can spend quality time together, enabling parents to be parents not caregivers. When time is short, they help families make the most of their precious time together.

EACH offers care to families with children and young people who:

- live in North, Mid and West Essex, Norfolk, Suffolk, Peterborough and Cambridgeshire
- have a condition with no reasonable hope of cure and from which they may/will die in childhood or early adulthood
- have a condition (or are diagnosed with a condition in the antenatal period) for which
  curative treatment may be feasible but can fail, such as children and young people with
  cancer and for babies born where intensive care has been deemed inappropriate and those
  with post-natal conditions which result in the baby experiencing unbearable suffering in the
  course of their illness or treatment.

Families can self-refer, or be referred by a health professional, by contacting the hospices by telephone (-1223 815100), email (<a href="mailto:ipswichadmin@each.org.uk">ipswichadmin@each.org.uk</a>), or via the <a href="mailto:website">website</a>.

# Mental health services and support

#### **Mental Health Crisis**

CPFT have a First Response Service (FRS) for people of any age who are distressed, worried about their mental health or experiencing something that makes them feel unsafe. It provides 24-hour access, seven days a week, 365 days a year, to mental health care, advice and support. Find out more about the First Response Service.

#### **Tier based Mental Health Services**

Support for mental health problems for all children and young people is Tier based

- Tier 1 Universal mental health services provided by professionals who do not specialise in mental health e.g. Teachers.
- Tier 2 Mental health services provided by practioners who specialise in mental health e.g. counsellors.
- Tier 3 Specialist Child and Young People's Mental Health Services, CYPMHs / CAMHs
- Tier 4 Inpatient / Highly specialised mental health services.

<u>Cambridgeshire and Peterborough NHS Foundation Trust</u> (CPFT) provides child and adolescent mental health services for children and young people up to age 17 who are experiencing emotional and behavioural problems and their families. They also support young people up to the age of 18 who have a learning disability and associated mental health problems. If you have concerns about a child under the age of 17 you will need to ask your GP to refer your child to these specialist services. If you are under 18 and have a learning disability you will either access children's services or will need a referral from your GP. If you are 18 or older then will need to ask your GP to refer you to adults' services.

Details of what is provided at each Tier in Cambridgeshire are set out below but there is also a service directory of all local NHS Mental Health Services in Cambridgeshire: https://www.cpft.nhs.uk/ourservices

Children with learning disabilities and or autism are being identified nationally as being at greater risk of being inpatients in hospitals for their mental health. Please send the section under Tiers 3 and 4 to read more about the work being done to help avoid admissions to hospital where it is avoidable.

### Tier 1 in Cambridgeshire

If you have concerns about your child talk to the class teacher and SENCO or your GP who can offer support and things to try.

<u>Keep Your Head</u> brings together good, reliable information on mental health and wellbeing for children and young people as well as their families and carers.

<u>YoungMinds</u> offers free confidential online and telephone support to anyone worried about the emotional and mental wellbeing of a child or young person up to the age of 25. You can call the free parents' helpline on 0808 802 5544 from 9.30am to 4pm, Monday to Friday or look at the website

#### <u>Tier 2 in Cambridgeshire</u>

<u>Kooth</u> is the free online service that offers emotional and mental health support for children and young people aged 11 - 19. Children and young people can have a "drop-in" chat with a counsellor or therapist or book a one-to-one session. No referral is needed to access this service – its self-serve.

<u>YoUnited</u> is a new partnership is bringing together emotional wellbeing services across the county for children, young people and their families, to improve access and support.

From 1 July 2021, local services will be provided by Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) under a partnership agreement with Cambridgeshire Community Service NHS Trust, Centre 33 and Ormiston Families. Together they will bring their expertise to support children and young people aged 0-25 with their mental health and wellbeing.

Children and young people will continue to receive mental health and emotional support during the transition of services to the new partnership, and we would like to reassure patients that they will continue to get the same level of care as they do now. Patients who will be seen by the new integrated service will be contacted in due course.

https://www.cambridgeshireandpeterboroughccg.nhs.uk/your-health-and-services/mental-health-learning-disability-services/children-and-young-people/

### Tier 3

There are a range of services for those experience moderate to severe mental health issues. The Children and Adolescents Mental Health (CAMH) Service work with those experiencing anxiety, low mood, depression, self-harm, obsessive-compulsive disorders, psychosis and the effects of trauma. <a href="https://www.cpft.nhs.uk/service-detail/service/child-and-adolescent-mental-health-services-camhs-63/">https://www.cpft.nhs.uk/service-detail/service/child-and-adolescent-mental-health-services-camhs-63/</a>

The CAMHS Single Point of Access accepts referrals from all professionals working with children and young people up to the age of 17 (or 18 if they have a suspected eating disorder or a neurodevelopmental diagnosis) who are registered with a GP in Cambridgeshire, Huntingdon, Fenland or Peterborough and are:

experiencing significant problems with their mental health (including eating disorders)

<u>CAMHS referral Jan 2020 Current.docx [docx] 315KB</u> seeking a neurodevelopmental diagnosis (ADHD or ASD)

For Cambridge/Huntingdon we only accept referrals for assessment of secondary age children. For primary age see community paediatricians by clicking on the link.

CAMHS referral Jan 2020 Current.docx [docx] 315KB

### Tiers 3 and 4

Preventing Inappropriate Admissions to mental health hospitals for children and young people with Special Educational Needs and/or Disabilities (SEND).

The NHS has committed to significantly reducing the number of children and young people with a learning disability, autism or both being cared for in an inpatient facility / hospital. There is help and support to work to help children and young people be treated and supported from home. The NHS working with the Eastern Region Parent Carer Forums has written a parent carer guide to these services: <a href="https://www.pinpoint-cambs.org.uk/wp-content/uploads/2021/02/Mental-Health-Information-for-parent-carers-March-2021-1.docx">https://www.pinpoint-cambs.org.uk/wp-content/uploads/2021/02/Mental-Health-Information-for-parent-carers-March-2021-1.docx</a>

### Dynamic Support Registers of Children / Young People who need extra support

Local health and social care services need to know who is most at risk of inappropriate responses by services. CCGs must now have a register of children and young people who have a Learning Disability, Autism or both and are at risk of going into, or are in, inpatient mental health settings. This is part of Building the Right Support. The register, called the **Dynamic Support Register (DSR)** should help children, young people and adults get the support they need before their problems get too serious and certainly before they need to go to hospital.

Your child, young person or adult should be on this register if they:

- Are currently in a hospital setting.
- Are referred for or accessing specialised services for challenging behaviour (e.g. intensive support services, specialist short breaks, special schools, residential care and supported living);
- Are subject to the provisions of the Mental Health Act or subject to Deprivation of Liberty safeguards.
- Have had a previous hospital stay (for example, within the last 5 years);
- Are / were involved with the youth or criminal justice system (for example, within the last 12 months).
- are children in 52-week educational placements.
- are in receipt of NHS Continuing Health care (CHC) funding.
- are in receipt of services from youth offending teams (YOT).

Children and young people up to the age of 18 who need extra support (see list on page 4) have the right to a **Care, Education, Treatment review (CETR).** A CETR should start when a hospital admission is being considered. You also have the right to ask for a CETR for your child or young person at any time if you have concerns about a placement breakdown, if there is a crisis or if there is a risk of inpatient admission.

If your young person is over 18, this will be called a Care Treatment Review (CTR).

CETRs are for children and young people who have learning disabilities and/or autism and who have been or may about to be admitted to a specialist mental health hospital (Tier 3 or Tier 4). The CETR makes sure that local services (social care, Special Educational Needs (SEN) Team and school or college) are involved so all issues can be addressed, and solutions found.

The NHS, together with Local Authorities are moving towards the aim of having one person, a Keyworker, as the central point of contact for a child or young person with a learning disability, autism or both who has a mental health condition, and their family members and carers, and the services involved in their care. At the moment in the East of England, the Keyworkers are part of an

18-month pilot project running in just two areas - Bedfordshire, Luton & Milton Keynes and Hertfordshire. Keyworkers in these pilot areas will only be for a small number of children and young people who:

- Have been diagnosed with a learning disability and/ or autism.
- Are under 18 years old or have yet to move to adult services.
- Are currently an inpatient in a mental health hospital, or are considered to be at risk of a hospital admission?

# Tier 4 in Cambridgeshire

There are a number of specialist in-patient units across Cambridgeshire that may treat our children and young people: occasionally specialist places are used further afield. Admission to these specialist units is made by the doctors and clinicians that are supporting the child or young person. Some admissions are planned, and some may be emergency admissions.

#### **Mental Health Crisis**

CPFT have a First Response Service (FRS) for people of any age who are distressed, worried about their mental health or experiencing something that makes them feel unsafe. It provides 24-hour access, seven days a week, 365 days a year, to mental health care, advice and support. Find out more about the First Response Service.

### Mobility

If your child has medium or long term mobility issues then you may need extra with the costs getting to a from appointments, If you are using mobility related services you may get help towards additional costs and be eligible for welfare benefits including <u>Disability Living Allowance</u>, grants such a <u>Family Fund</u>, the <u>Motability Scheme</u> and the <u>Blue Badge scheme</u>.

### Neurodevelopmental disorders, neurotypical and neuro-diverse

Neurodevelopmental disorders are disabilities in the functioning of the brain that affect a child's behaviour, memory or ability to learn including, dyslexia, attention deficit hyperactivity disorder (ADHD) and autism. Neurodiversity is a term that refers to the natural differences between people and was coined in the late 1990's by Judy Singer, an Australian sociologist. It can be compared to terms such as race, culture, class and gender and is useful to describe people with varying characteristics and behaviours of neurodevelopmental conditions alongside the "neurotypical" majority in a non-prejudiced way. This can be helpful as it's a more positive way of thinking about these as differences rather than deficits. Many people who are no neurotypical or neurodiverse have significant strengths and talents because of not seeing and processing the world in the same way.

The Children's Occupational Therapy (OT) service helps children and young people (CYP) participate in normal everyday activities such as play, participation in school/nursery as well as managing personal care (dressing, bathing, getting on and off the toilet and getting in and out of the bath). They support children between 0-18 years old, and those up to 19 years of age if attending special school provision.

They also support CYP by giving advice on adapting environments both at home and at school in order to make these safe and accessible. We want to help children and young people lead full and happy lives, to realise their potential and to take part as valued members of their community. We want to support a family to help their child.

The Occupational Therapists and support staff work as part of a multi-disciplinary/multi agency team to provide an integrated family centred approach to therapy provision.

### Coordination and motor skills online learning

The Royal College of Occupational Therapy states that a person's sensory issues must be considered in the context of their occupational engagement and performance in the relevant environment. Goals/ outcomes must be clearly related to the occupational engagement, performance and participation of a person and intervention must be regularly reviewed for effectiveness.

Sensory strategies that can be used within the framework of Occupational Therapy models of practice aim to:

- Manage (not change) the sensory needs of the person.
- Management through adapting the environment, modifying the task or developing strategies to self-manage their sensory needs.

Coordination and motor skills online-learning - We offer support to children, young people and their families through strategies, advice and goal setting tools available via our website. If further help is required, a referral to our service can be made.

Our website gives strategies and advice as well as on-line training which can be accessed by anyone.

This is a specialist services and referrals are through your GP. The **Referral Form** and **Guide For Referrers** can be found on the **contact page**. If you are over 18 you can ask your GP for a referral to this service.

### **Orthotics and Prosthetics Service**

<u>Cambridgeshire's Service</u> is offered from Addenbrooke's Hospital. Referrals will be through GP and specialists, but should you need follow up advice and care you can contact the service for support.

### **Passports for health**

There is also a general healthcare passport template. Use it at hospitals, clinic visits or GP appointments. Or keep a spare for holidays or one in the car glovebox in case of emergency. Download a general Healthcare Passport

Mencap and NHS England created a short emergency version for the COVID-19 outbreak to enable healthcare professionals to know immediately about your child's needs. Download the <u>2020 COVID-19</u> 'Grab and Go' Healthcare Passport.

You can also find a hospital passport in the Hospitals section (add link)

#### Pinpoint Cambridgeshire – free workshops and parent to parent support

Pinpoint is the Parent Carer Forum for Cambridgeshire. We support parent carers of children and young people aged 0 -25 years with additional needs or disabilities. As a parent carer forum, we enable the Local Authority to fulfil its statutory requirement to listen, engage and work together with parent carers for the benefit of children with Special Educational Needs and Disabilities (SEND) and their families.

Pinpoint offers support and signposting to services for parent carers through regular Tii Hub drops ins. They offer a wide range of workshops and information sessions, most of which are online, and are free to attend. They can be booked via <u>Pinpoint's website</u>.

#### Personal Independence Payments – see welfare benefits

### **Physiotherapy**

Paediatric <u>physiotherapy</u> is the assessment and support of children and young people from birth to 18 years (19 years for some young people in specialist education). They work with the child/young person (CYP), their family and others supporting the child or young person to encourage each individual to get the most out of their lives, and fully develop their potential.

They provide a community-based physiotherapy service; working out of clinics and where appropriate, in other settings such as school and home. A multidisciplinary approach is taken,

working closely with Paediatricians, Speech and Language Therapists, Occupational Therapists and others supporting the CYP.

Referrals are considered from health professionals, including GPs, School Nurses, Community Paediatricians, Health Visitors and Hospital based services. We will also consider referrals from social care, and education professionals. All referrals are triaged by Senior Physiotherapists to determine whether physiotherapy is likely to be beneficial. The referrer and the young person or family will be informed of the outcome of this triaging process. If you are over 18 you can ask your GP for a referral to this service.

#### **Prescriptions**

Prescriptions will be free until a young person becomes 16 (or 18 if they are in full time education). If you receive Universal Credit, this is extended to 20. They will continue to receive free prescriptions as an adult if they have the following medical conditions:

- A permanent fistula (for example, a caecostomy, colostomy, laryngostomy or ileostomy) requiring continuous surgical dressing or requiring an appliance
- a form of hypoadrenalism (for example, Addison's disease) for which specific substitution therapy is essential
- diabetes insipidus or other forms of hypopituitarism > diabetes mellitus, except where treatment is by diet alone
- Hypoparathyroidism
- myasthenia gravis
- myxoedema (hypothyroidism requiring thyroid hormone replacement)
- epilepsy requiring continuous anticonvulsive therapy
- a continuing physical disability that means the person can't go out without the help of another person
- undergoing treatment for cancer, including the effects of cancer/treatments.

### **Puberty**

Although many young people with special needs experience delays in achieving developmental milestones, puberty usually occurs at the same age and involves the same changes as typically developing children.

It is normal for all parents to feel anxious about this stage of their child's development.

Parents may worry about hygiene, period management, emotional meltdowns, emerging sexuality, masturbation and inappropriate touching of others. They may also have fears about the increased risk of sexual abuse and the possibility of casual sexual relationships, pregnancy and STIs.

Parents may also be concerned about how their child will cope emotionally with puberty changes and their emerging sexuality, now and in the future.

Parents and young people can investigate support from their local GP or Cambridgeshire's NHS <u>icash</u> service. Our section on Sexual health may also be useful (add link)

### Sensory Impairment - hearing and sight loss

The term sensory impairment encompasses visual loss (including blindness and partial sight), hearing loss (including the whole range) and multi-sensory impairment (which means having a diagnosed visual and hearing impairment with at least a mild loss in each sense, or deaf blindness).

The Health Services for children with sensory impairment is provided at the Child Development Centre by a Multi - Disciplinary team of Community Paediatricians, Speech and Language Therapists, Occupational Therapists and Physiotherapists. This health service works closely with the Sensory Impairment Service provided by the Local Authority as part of the SENI team.

More detailed information about the Sensory Service Team can be found <a href="here.">here.</a>

### **Sensory Processing Differences and Difficulties**

When a child doesn't respond in the way they are expected to, it could be because they are finding something too intense or overwhelming and they just can't cope. Alternatively, it could be that they need even stronger sensory activity to get the message from their senses. There are 5 senses that you will probably know: Sight, Sound, Smell, Taste and Touch, but there are also 3 more - Vestibular (movement and balance) Proprioception (body awareness) and Interoception (how our body feels inside).

Cambridgeshire's Children's Occupational Therapists have the skills to identify an individual's sensory strengths and differences and their impact on daily activities as part of their assessment of a person's occupational performance.

Ayres Sensory Integration Therapy (SIT) is a tool used by some occupational therapists to address a person's sensory needs. SIT aims to change a person's sensory processing through direct, intensive therapeutic input and is delivered by occupational therapists who have undertaken certified postgraduate training. The research evidence is inconclusive regarding the impact of SIT on daily life activities.

There continues to be much debate and controversy regarding Ayres sensory integration Therapy. Evidence for SIT remains largely anecdotal in nature and there remains little conclusive scientific evidence to support the use of SIT in the general population.

Therefore, in line with the strongest evidence base, Cambridgeshire Children's Occupational Services do not provide Ayres sensory integration.

Sensory Processing Disorder (SPD) is not included in the Diagnostic and Statistical Manual (Fifth Edition); sensory differences are considered a symptom rather than a diagnosis. The Royal College of Occupational Therapy (RCOT) do not therefore support the use of SPD as a diagnostic label.

The <u>Cambridgeshire Children's Occupational Team</u> do provide help to support Sensory Integration and some <u>useful resources to support sensory differences</u>.

### SCIP and SCIP card - Special Needs Community Information Point and Card

SCIP (Special needs Community Information Point) is a Cambridgeshire County Council information and advice service for families with 0–25-year-olds with a disability or additional needs. By joining SCIP you get

- SCIP Card
- Activities Passport
- Email updates on local events and activities
- <u>Information booklets on local activities/support by area</u>
- Request information specific to your child
- Carers Magazine
- The SCIP Co-ordinator can also be contacted for information specific to your family's needs.

#### Join here

The SCIP card can help to show that your child/young person has a disability or additional need. You need to be on the SCIP Database to get a SCIP Card. It can be used:

- as proof that your child /young person has a disability
- if they need to use facilities provided for disabled people
- if you need to ask for assistance.

SCIP\_Card\_Factsheet50KB-pdf

#### **Sexual Health**

If you're looking for contraception, treatment for sexually transmitted infections, HIV care and treatment or related advice in Cambridgeshire, <u>icash NHS</u> can help.

Icash have created three bespoke hubs across the county, bringing all aspects of sexual health under one roof. They also have three smaller clinics.

Icash also work with Terrence Higgins Trust, who provide community outreach services including free condoms, Chlamydia screening and sexual health advice and signposting. They offer routine sexual health screening; you can order a kit by <u>clicking here</u> and it will be delivered to your door in plain packaging. Then complete the test and pop it back to us freepost. if you can't order a kit online, please call us on 0300 300 3030.

They have clinics across Cambridgeshire – you can find details here.

Pinpoint's Preparing for Adulthood parent group has worked with charity DHIVERSE in Cambridge, which runs a <u>sexual health and relationships programme specifically for people living with a learning disability or difficulty</u> and their parents and carers.

<u>DHIVERSE</u> runs a six-week ABC programme for young people with LDs to help them develop skills around Awareness, Balance and making Choices concerning relationships and sexual health. The programme covers:

- Understanding relationships
- · Being assertive and communication skills
- Keeping safe and taking risks
- Staying safe online and in the community
- Sexual Health
- •

### Sight Tests and glasses

All children will get their eyesight checked as part of the free NHS checks at different ages including when they start school. - these are intended to ensure children don't slip through with unnoticed sight issues. But you don't need to wait for those - if you are worried you can get a free check done. Getting a professional (optician/ optometrist/ophthalmologist) to look at your child's sight and check what they can and can't see is easy and free. And the professionals can do sight tests even on children who can't yet read or don't know their alphabet - they get a different test which works for their age. And it even works if they have difficulties talking, following instructions or concentrating.

Book an appointment with your high street optician. Children with exceptional needs: Local opticians will usually have specially trained staff who can advise whether they can do a test given your child's needs - they should be able to meet the needs of most children and babies. If they cannot meet your child's needs, request a referral from your GP or the optician to a specialist service at the hospital.

### **Sleep Service**

Children often experience short spells when sleep patterns change but prolonged sleeplessness, broken sleep or falling asleep at inappropriate times should be talked through with your child's GP to check what's going on. Cambridgeshire also has specially trained sleep practitioners in who can work with families to help overcome sleep issues such as night waking, trouble settling to sleep, night-time routines and challenging behaviour at bedtime. You can call them 01480 379 800 Email: <a href="mailto:Community.SupportServices@cambridgeshire.gov.uk">Community.SupportServices@cambridgeshire.gov.uk</a>. The service can advise on young people too but over 18-year-olds should ask their GP for advice. They have produce a sleep management guide.

### Specialist equipment

Some health needs will mean your child needs specialist equipment (add in about new ICES provider)

# **Speech and Language Therapy**

The aim of this service is to provide comprehensive packages of care for children and young people up to school leaving date who have difficulties with speech, language, communication and/or swallowing.

Packages of care are provided on the basis of need and may include:

- comprehensive assessment
- indirect intervention i.e., through parents and staff in educational and care settings
- direct intervention (individual and/or group)
- specialised training for parents and staff in educational and care settings
- advice to other agencies on the speech, language and communication training that they deliver

#### Benefits of the service include:

- positive contribution to the competency of other professionals in identifying and supporting children who have speech, language and communication needs.
- improvement of children's speech, language and communication skills
- positive contribution to educational, behavioural and social outcomes

Speech and Language therapy is provided at main health centres/clinics in Cambridge, Ely, Huntingdon, March, Chatteris and Wisbech and the surrounding villages.

Therapists also visit mainstream nurseries and primary schools depending on the needs of children in that school. Speech and Language Therapists also provide therapy at the special schools in Cambridgeshire.

The service offers an open referral system, but the majority of referrals come from health visitors or school staff. For details of how to access our service, please **click here** or watch the animation below

#### Suicide – help for individuals and families

### **Mental Health Crisis**

CPFT have a First Response Service (FRS) for people of any age who are distressed, worried about their mental health or experiencing something that makes them feel unsafe. It provides 24-hour access, seven days a week, 365 days a year, to mental health care, advice and support. Find out more about the First Response Service.

Whatever the mental or physical health diagnosis, if the person you care for has talked about suicide it's important you take them seriously. In a crisis, help is available 24/7 from the Samaritans on **116 123**. In an emergency, call **999**. The <u>Zero Suicide Alliance</u> offers free online <u>suicide prevention</u> <u>training</u> which takes just 20 minutes to complete. Offering the right type of support to someone who is feeling suicidal is crucial. <u>LivingWorks</u>, a leading provider of suicide-alertness training, advises following the acronym TALK:

#### T - TELL

Someone who is feeling suicidal will be telling you how they feel but perhaps not very directly so be aware of the signs and learn to read them. Do not dismiss them or trivialise them

#### A - ASK

If you think someone is considering suicide always ask them. You can't give them the idea of suicide simply by asking, and it is important that you do ask. If they say 'no' you haven't lost anything, and if they say 'yes' you have a chance to help.

#### L - LISTEN

Don't rush them or judge. Tell them 'this is important'. Don't try to offer solutions, just listen. Listening stops people feeling alone, gives hope and provides emotional release.

#### **K - KEEP SAFE**

Don't promise secrecy, but don't leave someone feeling suicidal on their own. Keep yourself and them safe.

Most people who feel suicidal simply want to end their pain, not their life. Many people who have had suicidal thoughts and/or made a suicide attempt look back later and say they are glad to have survived and that the right intervention at the right moment made all the difference. There is nothing inevitable about suicide. It is often a question of knowing how to help and supporting someone through a crisis. More help is also available from these organisations:

**CALM Helpline**\_is dedicated to preventing male suicide and offers confidential emotional support for men through their helpline. Telephone: 0800 58 58 58. Calls are free from landlines and most mobiles. Webchat (5pm-midnight)

**Grassroots** is a suicide prevention charity.

<u>Maytree Sanctuary</u> is open to anyone in a suicidal crisis for a one-off short stay in a safe place. The service is free, and it is open to anyone in the UK. It offers a quiet place to reflect and time to talk in confidence. Telephone: 0207 263 7070

<u>Papyrus Hope line UK</u> is a national confidential helpline for young people at risk of suicide. Telephone: 0800 068 41 41

Samaritans Call 116 123. This is a free 24-hour helpline and offers a safe place to talk.

<u>STOP Suicide</u> is an award-winning suicide prevention campaign which reaches across Cambridgeshire and Peterborough. It is led by the charities <u>Mind</u> and <u>Lifecraft</u> in Cambridgeshire, Peterborough and Fenland.

<u>The MindEd Trust</u> is a Registered Charity which is focused on the prevention of mental illness in young people and early intervention strategies for those experiencing trauma.

**CHUMS** is a Mental Health and Emotional Wellbeing Service for children and Young People.

### **Transforming Care**

Transforming care is an NHS programme which is all about improving health and care services so that more people can live in the community, with the right support, and close to home. Transforming Care can improve the lives of children, young people or children and adults with Autism and/or learning disability, behaviour that challenges and/or mental health issues. It is about improved support in your community.

This is so that you don't have to go to a mental health hospital or residential unit far away from where you live, because there are no services to meet your needs in your local area. (use rest of drop down from existing page)

The Eastern Regional Parent Carer Forums and Cambridgeshire's Parent Carer Forum, Pinpoint, have produced a <u>parent carer guide</u>.

### Welfare Benefits and financial help

Having a child with health needs can mean you need to pay for extra help, do more caring for your child, do more washing, need extra equipment and pay costs for travelling to medical appointments. Whilst some things you do for your child will be the same as those parents do for a child of a similar age, there may be additional things you do because of your child's health needs. You or your child / young person may be entitled to additional welfare benefit support. Many of the welfare benefits do not take into account what you earn or your family income – they look at what the needs are. Contact a Family have information which covers all welfare benefits that may be applicable.

#### Wheelchair Service

The <u>wheelchair service</u> is for residents currently registered with a GP in the Cambridgeshire and Peterborough NHS CCG areas, and who meet the NHS Eligibility criteria for the provision of wheelchairs. AJM Healthcare is the appointed NHS Wheelchair Service Provider. The service will provide you with all NHS wheelchair services, including:

- clinical assessments
- specialist seating
- delivery
- repairs and maintenance
- collection when the wheelchair is no longer required

A wheelchair assessment establishes your clinical needs, and a prescription is made for the right wheelchair for you. Your assessment will take place at our wheelchair clinic in Huntingdon, or at home or another appropriate location, i.e., school or health care setting.

If you are using this service you may get help towards additional costs and be eligible for welfare benefits including <u>Disability Living Allowance</u>, grants such a <u>Family Fund</u>, the <u>Motability Scheme</u> and the <u>Blue Badge scheme</u>.

### **Section 6: New Health Offers**

### A new hospital for Cambridge - Cambridge Children's

Cambridge will be getting a new children's hospital. <u>Cambridge Children's</u> will sit at the heart of the Cambridge Biomedical Campus – Europe's leading life science hub. It's not open yet but when it is will respond to the health challenges facing children in the United Kingdom through innovative clinical programmes and research.

The new hospital will focus on enhancing healthcare delivery in the east of England, extending expertise to families and the community to maximise a child's potential for a healthy and happy life. Research will position Cambridge Children's to lead by example and provide value to the NHS.

### **Autism Centre for Excellence**

Working with the University of Cambridge, Autism Centre for Excellence will be the first national clinical and research centre for autistic people in the UK. It will bring a unique mix of compassionate and experienced professionals together under one roof, to support autistic people across the spectrum, whatever their age, life stage or challenge.

ACE are working in partnership with Cambridgeshire and Peterborough Local Authorities to bring about better understanding of autism and see what improvements can be made to enhance local services.