

CHAPTER 7

Health and medical matters



If your child has health issues, you'll need to think about the switch from children's to adult health services as part of their transition plan and ensure they get the support they need. We found it was useful to try to predict changes in their health needs and to help our children become more responsible for their own health.

As we mentioned in Chapter 1, Statements of SEN have been replaced by Education Health and Care (EHC) Plans and there is a timetable for transferring young people with Statements to these new plans. EHC plans can include more about health needs and can carry on until a young person is 19 or even 25 in some cases. This should help in the planning for transition to

adult health services. But it remains the case that a number of things will change for your child in terms of health services.

As an adult, your child will use different, often more general, health services. For example, a young person with joint problems may always have been seen on the same children's ward, but once they reach 18 they'll need to use a general hospital ward where the majority of other people may be elderly. Other therapies and services may stop. Some of the services provided for children and families don't have equivalents in adult health services. For example, you might get family therapy from the Child and Adolescent Mental Health Service (CAMHS), but not from adult mental health services. For many, the biggest change will be if you have had a community paediatrician from Seaside View Child Development Centre overseeing your child's health needs; when your child reaches 18, their GP will take over.

In this chapter we will explain how health services are organised and how the transition from child to adult health services should work.

UNDERSTANDING THE NHS

The NHS is a national health service but if you have had to make significant use of health services over the years with your child, you will have noticed that it is a complex organisation and has different parts at a local level. Most of the time we can ignore this but sometimes it is useful to have an idea of how things work. There have been changes to the way many health and social care services are delivered locally and nationally since changes in the law were introduced through the health and Social Care Act 2012. At a local level, the council has a stronger role in shaping services and has taken over responsibility for local health improvement. There is now a Health and Wellbeing Board that is made up of people who

commission (pay for) health and social services, elected representatives and representatives of Healthwatch. This board decides the best way to improve local health and wellbeing. The way the money for health is spent is decided by clinical commissioning groups, which give GPs and other health workers responsibility for making those decisions. And the Care Quality Commission has to make sure that services meet safety and quality requirements.

Hospital or 'acute' services are provided locally by the Brighton and Sussex University Hospitals NHS Trust (at the Sussex County, Princess Royal Haywards Heath and Royal Alexandra Children's hospitals). The Sussex NHS Foundation Trust provides mental health and learning disability services. Sussex Community NHS Trust provides a range of community health services including community nurses; continence services, rehabilitation, wheelchair and equipment services, and speech and language therapy. Some health services are provided by other partners, for example substance misuse services are provided by Pavilions (a collaboration between Cranstoun, Surrey & Borders NHS Partnership Foundation Trust, Equinox, Brighton Oasis Project, YMCA Downslink Group, and Cascade Creative Recovery).

The **My Life website** is a great place to start for information about local health and social care services - www.mylifebh.org.uk You can get help to use this site at Hove, Jubilee or Whitehawk Library.

Healthwatch is the health watchdog intended to provide information about health services and give users a voice in how they are run. If you need advice or information about health services in Brighton and Hove, or if you're not happy with the service you or your child have received, Healthwatch should be able to help. They will listen to your concerns, suggestions, queries and comments on health services. They will use this in

their role of giving feedback on health services from the point of view of users. But they will also help to sort out problems on your behalf and if necessary inform you about how to make a complaint. Email help@healthwatchbrightonandhove.co.uk or call 01273 234040.

If you decide to complain it is a good idea to get advice from the **Independent Complaints Advocacy Service (ICAS)**. ICAS is a free and independent service that can help you make a complaint about your NHS care or treatment. The advocacy complaints service will support Brighton and Hove residents who need help to resolve a complaint about healthcare commissioned or provided by the NHS. Brighton and Hove Impetus is setting up this new service. Call 01273 229002 or email info@bh-icas.org to ask for an advocate to call you back.

YOUR CHILD'S GP

Your child's GP will be central to their health care from 18 – so it pays to build a relationship with them in advance. Once your child is an adult, the GP will not be able to discuss their health with you in the way they can about a child. Make sure you talk to them early if there are things to discuss.

Now is also the time to think about whether your child has the right GP to support them in adulthood. It's often good to stick with the same GP and develop a long term relationship, but it's possible to change if you think it would work better. You could change to another doctor in the practice, or move to another practice altogether. The easiest way to find another GP who's accepting new patients is through the NHS Choices website – www.nhs.uk. The website includes service reviews from other patients. If you're not online, there should be a list of local GPs at your local library or call the Healthwatch helpline.

If your child is currently under the care of a community paediatrician, they should share information with the GP – but you may need to help the GP fully understand your child’s condition or learning disabilities. The truth is, if you’ve spent years going to specialist appointments and reading reports about your child, you shouldn’t be surprised to find you’re as much an expert as the GP at first. Be ready to work together.

THE TRANSITION TO ADULT HEALTH SERVICES

For many services the switch from child to adult services happens at 18, but this can vary. Community paediatricians can see a young person until they reach 19. In-patient and out-patient care at hospital will usually be alongside adults from 18. For acute health care, your child may attend adult clinics from 16 – although some specialist consultants may continue to see a young adult after 18. Some services, like speech and language, may stop seeing your child at 16 if they leave school then. CAMHS (Child and Adolescent Mental Health Service) may continue to see existing patients until they’re 19, although new referrals are passed to adult mental health services. And there is a service to help bridge the gap between CAMHS and adult mental health services (see TAPAS on page 163). GPs see people of all ages of course but they will start to expect young people to see them independently from 16 or 17.

It’s important to find out what happens with the specific services your child uses and to plan ahead. Your child should not be discharged from children’s health services until their care has been transferred to adult health services.

Health services are responsible for identifying whether a young person is likely to have on-going healthcare needs and to make sure these needs are met when they leave school or become an adult. They should ensure there’s a clear process for

transferring responsibility and information, but parents also have a role in helping this go smoothly.

Children's health services are free, but adults have to pay for some things like dental care and prescriptions. However, if your child is getting benefits or on a low income, they can get free dental treatment, free prescriptions, free eyesight tests and vouchers for glasses, free wigs, boots or other equipment and transport to and from hospital.

PARENT TIPS

- ☺ Different health services have different arrangements – wherever possible, ask staff what will happen when transition to adult services takes place. Talk to staff and other parents to get information about choices you could make now
- ☺ There are steps you can negotiate now that will ease the change. For example, you could arrange to visit a new clinic or ward before your child needs to attend. Some services offer a joint appointment with children's and adults' services just before the swap to adult services. Ask if this is an option

Transition planning and the health care plan

In Chapter 1, 'Planning for your child's future', we covered transition planning for children who have a Statement of SEN or an EHC plan. Some of our children have ongoing health needs and planning for them will be central to their plan. Other children may not have any particular health needs and you'll just need to make sure their GP knows them and their needs in good time.

If your child does have ongoing health needs, health professionals are unlikely to be able to attend many (or perhaps any) of the annual review meetings at school that will look at transition planning and preparing for adulthood, but they can be asked to make a written contribution. Let the school know who's involved in providing health services for your child, so they know who to ask. New professionals, like a rehabilitation medicine specialist, adult neurologist or OT (occupational therapist), may need to get involved in planning for transition.

From Year 9 onwards annual reviews should have a focus on preparing for adulthood and this should include support to maintain good health in adult life. Health professionals involved in the management and care of your child should provide advice in writing and where appropriate, attend the review meeting in Year 9. If your child has health needs that will continue into adulthood, the person who currently oversees their care should draft the first 'health care plan' following the meeting and this must fit alongside the EHC plan. They should advise on services likely to be needed and discuss arrangements for transfer to adult services with your child, the GP and you. Later, having obtained your child's consent, they should make any referrals to adult health services and arrange the transfer of records.

If your child is also likely to have care and support needs at 18 from adult social care they should also have a transition assessment for this. This can be carried out alongside any health transition assessment. And again the EHC plan can be used to coordinate all three.

As with all transition planning, the health care plan is not a one-off document and it should be changed and added to as your child moves through transition. It should be completed in your child's final academic year and may need updating again just before they leave school.

PARENT TIPS

- ☺ If you feel a particular health professional understands your child's situation, ask them to provide a full report or come to the transition meeting
- ☺ If they agree, you need to give them several months' notice. Be prepared to remind them about the meeting a couple of times, including the week beforehand
- ☺ Notify the person organising the transition meeting that the health professional has agreed to prepare a report or attend the meeting

ENCOURAGING INDEPENDENCE

As parents, we're used to looking after our children's health and we're good at spotting when they're unwell or in pain. Chapter 2, 'Involving your child', covered our role as parents in helping teenage children make choices and communicate their options so they can become as independent as possible as adults. This applies to their health needs too.

Some young people with complex health and social care support needs will require help to express themselves. Other young people may have such profound needs they will remain dependent on adults for on-going care. But if it's possible, letting others know you feel ill or that something hurts is an important skill to learn.

It's not an easy subject, but in recent years there have been shocking revelations about the treatment of vulnerable people in health and social care settings. In the worst cases, people have been hurt or died unnecessarily. These awful cases are exceptional, but they have highlighted how services have sometimes ignored parents' and patients' wishes, dignity and

rights. These revelations have made it more acceptable for us to ask searching questions.

It is okay to expect more information and to ask to have a central role in the decisions made about your child's life. It's understandable if you want to keep a close eye on the health and care services your child gets as an adult – but encouraging them to think their feelings and opinions matter and should be listened to, is also part of keeping them safe in the future.

The progress towards a young person gaining as much independence as possible begins with us as parents gradually handing over responsibility to the young person. For most young people, the road to independence includes learning to look after their own health needs.

Young people communicating their health needs

Young people with disabilities, chronic illnesses or learning disabilities have to learn to communicate their health needs as much as possible.

It's important to develop skills, relationships and confidence when speaking to health workers. An early step may be to ask health professionals to direct questions to your child. Some may be so used to addressing the parent, they need firm prompting.

You may need to help your child learn the right vocabulary or signs to talk about their body and health. One day they will need to be able to let other people know where it hurts or feels funny, without you to explain for them. Make sure your son or daughter knows the difference between a polite adult asking, "How are you?" but not expecting a real answer, and a doctor who wants them to talk about their health.

'If anyone were to ask me what message I might have for others I would tell them that they should listen to, believe and respect young people. It's very difficult to tell anyone how you feel when they won't listen; if you aren't believed then you stop believing in yourself; if you're not respected then you lose your self-respect and everyone needs self-respect'

(Sue 18)

A word about the Mental Capacity Act and health

When a young person reaches 16, they're legally classed as an adult in terms of decision making about their health. The Mental Capacity Act (MCA) covers your child's rights to make their own decisions if they have 'mental capacity' – including decisions about health and medical treatment. It also sets out how decisions should be made with and for them if they don't have the capacity to decide for themselves. In these circumstances a medical professional is likely to be the decision maker and not you as parent once they are 16. But the decision maker should get the views of those close to the young person unless it is a medical emergency. See page 37 for more details on the MCA.

Bear in mind that children younger than 16 can also be judged as being competent to make their own decisions about health care if they are seen to have the necessary maturity and understanding. For example a GP or clinic could prescribe contraceptives in confidence to a 15 year old who asked for their parents not to be involved.

Confidentiality and medical records

The confidentiality of patients' health information is enshrined in codes of professional conduct. Everyone has the right to have a copy of their medical records and the records should be presented in a format that patients understand. If the patient is

under 18, anyone with parental responsibility can apply to see their child's medical records, but if the GP or doctor responsible believes that your child is competent to make their own decisions about health, they should check that they consent to this. Once a young person is over 18 you'll always need a letter giving their consent, or a 'power of attorney' to see them.

If for some reason you are denied access to your child's medical records or their records have been lost, contact Healthwatch for help – see page 149.

MANAGING MEDICAL APPOINTMENTS

Assessments, appointments, consultations or visits by health professionals can be stressful, worrying and tiring. It's common for healthy, fit adults to forget a lot of what has been said and even more difficult for tired or anxious people. Bad news or painful information can come as a shock and trying to cope takes all your effort. It can feel difficult to ask the right questions to get the information you need. You may have lots of experience in handling this – but have you started to teach your child how to cope?

'I have found that even the most informed doctor or health person cannot provide the most basic of information if you don't phrase the question in the right way. It's frustrating because often you don't know the right question to ask. The only way as I see it, is to keep making it clear that you need clarity and detail. When I had to deal with the last problem which didn't seem to have a solution, I asked the doctor what the possibilities were, and this got a much better response.'

The coping question

Sometimes parents and young disabled or chronically sick people may say things are fine and they're coping, even when it's not true. Many parents and young people may also have

been asked if they're coping, and when they say things are difficult, the other person switches off. It's easy to be discouraged from being honest in future.

But you and your child face your challenges 24 hours a day, seven days a week. You know what the problems are and what some of the solutions may be. Tell the professional what your concerns and needs are, and help your child do the same.

How to be prepared

Being prepared for each appointment with health professionals can be a real help. When you can think clearly at home, it's helpful to talk to your child beforehand and write down all the things you both want to discuss.

Take a list of questions into the consultation, and write down the responses. It may take longer and you may feel awkward at first, but when you get home you're more likely to have the information you need. Then you and your child can talk it over to make sure your child has understood too. You or your child could also choose a friend to go with you to prompt you and remember what's been said.

Preparing can also be a positive opportunity to talk about issues together, as well as helping your child practice doing more of the thinking themselves as they get older.

'There is an underlying principle that we should never assume anything. We're always left having to assume, because we're not informed adequately by the 'experts'. It's imperative to find out the facts, because, as we have all experienced, our assumptions are often incorrect.'

PARENT TIPS

- ☺ Think ahead about the information you need from a consultation. Write questions down and involve your child as much as you can in this thinking process
- ☺ Remember your child's worries may be different from yours. Ask them!
- ☺ Is there a leaflet or a web page you can look at with your child so they can see where they are going or what equipment they may see there?
- ☺ Politeness, firmness, persistence and a good sense of humour help if the medical professional doesn't seem to 'get' what you and your child need from them

LEARNING DISABILITY AND HEALTH SERVICES

Specialist services for adults with learning disabilities in Brighton and Hove are provided by the Community Learning Disability Team (CLDT), a partnership between Brighton & Hove City Council and Sussex Partnership NHS Foundation Trust. The CLDT provides specialist health and social care services to adults with learning disabilities and their families, including:

- Care management and social care
- Community nursing
- Occupational therapy
- Physiotherapy
- Psychiatry
- Psychology including behaviour support and counselling
- Speech and language therapy

The CLDT provides and purchases a wide range of support services, day services and accommodation for adults with

learning disabilities. Access to them is through the social care Access Point. See Chapter 6, 'Social care', for more information or visit the www.brighton-hove.gov.uk website which has a section on social care and health. The contact number for the CLDT is 01273 295550.

The CLDT also has learning disability liaison nurses who ensure adults with learning disabilities get the right care in hospital. They can support with planned and emergency admissions, outpatient appointments and hospital discharge. They work across the Royal Sussex County Hospital, the Sussex Eye Hospital, the Princess Royal Hospital and Hove Polyclinic. It is a good idea to have a Hospital Passport that your young person can take with them to hospital which should contain all the important information needed to help hospital staff to understand how to take care of them. You can get a hospital passport from the liaison nurses or from CLDT. The liaison nurses can be contacted on 01273 696955 ext. 64975.

The CLDT also has a Health Facilitator who works with GP practices and other health services to help them better understand and look after the health of adults with learning disabilities. The Health Facilitator works on different projects, delivers training and develops resources and information.

Annual health checks for people with learning disabilities

People with learning disabilities aged 14 years and above in Brighton and Hove are eligible for an annual health check and health action plan from their GP practice. The annual health check appointment should be longer than a usual appointment, so there's time to talk about a range of health issues and not feel rushed or confused. The health check can be done by a GP or nurse, or sometimes by both – each practice has its own arrangements. Local GP practices have had training from the Health Facilitator so they understand more about learning

disability and how to be helpful and clear. After the health check, the GP or nurse writes up a health action plan and sends it to the patient.

Parents who have been to one of these health checks with their son or daughter have been impressed with how thorough it is and feel the GP is better placed to support them as a result. Starting annual health checks from age 14 is a great way to improve the transition to adult health care. If your son or daughter is eligible for an annual health check and has not been offered one yet, you can contact your GP practice to request one and tell them the Health Facilitator at CLDT can give support and advice if they need it. There is a 'Step by Step Guide to Health Checks' which can be provided by CLDT.

SEXUAL HEALTH SERVICES

One of the issues parents say they find tricky is thinking about their teenager wanting to have a sex life. But sticking your head in the sand about this could have life-changing consequences. See Chapter 4, 'Social lives and relationships', for more about this - but it's worth knowing what sexual health services can offer. This service provides:

- Contraception, including long term and emergency contraception
- Pre-menstrual syndrome (PMS) advice
- Young persons' health clinic
- Smear tests
- Pregnancy testing and counselling
- Rubella screening and vaccination
- Chlamydia testing for under 25s

The Sexual Health and Contraception (SHAC) Service can put you in touch with the nearest clinic, or you could look at the Brighton and Hove sexual health website for young people,

parents and professionals (www.swish.org.uk). It has lots of helpful information.

MENTAL HEALTH SERVICES

The teenage years can be an emotional rollercoaster for young people. As parents we know they'll face the physical changes of puberty, but there are also psychological changes that will affect our children's behaviour and emotional wellbeing. Many teenagers become more moody, self-centred or reckless. If you could do with new ideas for dealing with their behaviour, a Triple P Teen positive parenting course might help. Call the Amaze helpline for information.

Many teenagers have times when they feel anxious or low. Local secondary schools and colleges usually offer counselling for young people. If your child doesn't want to be seen seeking help at school, there are several alternatives. The Where To Go For website is the best place to check what is available locally www.wheretogofor.co.uk but the options include the Young People's Centre (YPC) in Ship Street, the Youth Advice Centre (YAC) in West Street, Counselling @65 in Blatchington Road and the counselling and wellbeing projects in Moulsecoomb and Whitehawk. There is also a local online counselling service called e-motion at www.e-motionbh.org.uk. The national 'Find Get Give' website (www.findgetgive.com) has local information on mental health support for young people too.

For some young people, the mental health problems of the teenage years may become more serious. And for a few, significant mental health issues may emerge. Persistent depression, high anxiety, serious eating disorders or really difficult or unusual behaviour are good reasons for looking for outside help. If you're worried about your son or daughter's mental health, you can talk to your GP and they may refer them to the Child and Adolescent Mental Health Service (CAMHS).

Schools and other professionals working with your child can also refer to CAMHS. CAMHS provides help with a wide range of mental health problems for children and young people up to 18, and their families. CAMHS workers are based in the community or clinics and include a variety of practitioners such as therapists and psychiatrists.

There's also a special service for 14 to 25 year olds provided by trained mental health workers known as TAPAs (Teen and Adult Personal Advisers). They're based in youth centres: YPC, YAC and the 67 Centre in Moulsecoomb. There are specialist TAPAs for lesbian, gay, bisexual and transgender (LGBT) young people at Allsorts Youth Project and for black and minority ethnic (BME) young people at the 67 Centre. Young people can walk in and ask for this service, or can be referred. The aim is to reach young people who find it hard to take up more formal mental health services. TAPAs can give short term treatment and bridge the gap to CAMHS or adult mental health services if needed. There is also an Early Intervention in Psychosis service that straddles CAMHS and adult mental health for young people age 14 to 25 who experience a first episode of psychosis.

If your child is 18 and no longer at school, they may be referred to Working Age Mental Health (also known as adult mental health services) which provides mental health care for adults. Young people already getting help from CAMHS should move over to this service at 18 – or if your child doesn't meet the criteria for adult mental health services, the CAMHS worker may suggest discharging them. Their GP would then take over their care. You can query this and ask for an assessment.

Working Age Mental Health Services are responsible for the provision of all mental health services for adults from 18 to 65. Services are wide ranging and include a Wellbeing Service, an Assessment and Treatment service and in-patient care.

There are also some independent organisations which can provide support. Young Minds is a national organisation which offers information and advice to parents. Locally, Mind has a 'Young People's Advocacy Worker' for 11-19 year olds. Young people or parents can contact them directly for support. Right Here is a local project that offers activities to support the mental health of 16 to 25 year olds. Allsorts Youth Project works with young people under 26 who are LGBT or unsure of their sexual orientation and/or gender identity. Services can include support around mental and emotional wellbeing.

Doc Ready (www.docready.org) is a new web app to help young people who are experiencing mental health issues to prepare for the GP appointment, and get 'doc ready' by building a checklist of what to talk about and learning more about confidentiality and rights. It's designed to get a two-way discussion between the young person and GP flowing more quickly, so both parties get the most out of the limited time they have available in an appointment. Your child can 'like' them on Facebook: www.facebook.com/getdocready or follow them on Twitter@DocReady.

Further help on health

Many national organisations specialise in supporting families and individuals with a particular health condition or disability, including broad ones such as Young Minds, Mencap and Cerebra and more specific ones such as Arthritis Care or Epilepsy Action. Contact a Family can provide details of the organisations relevant to your child. Some of these national groups recognise that the needs of young adults are different and provide specialist information, support or training for people in transition. Try asking them what they have available for young adults.