

## **Transition Considerations For Young People with complex Needs May 2021 moving to adult service**

### **Overview**

When a young person reaches adulthood the providers of their healthcare, financial support and educational will invariably change to adult services. This document aims to give an overview of some of the key changes and signpost to further sources of information required for young people and their families living in Bristol and the surrounding areas.

### **Medical Care**

#### **Community paediatrics**

Community paediatricians currently look after and co-ordinate care for young people until they are 18 years old. There is not a direct adult comparator and young adults care is generally then co-ordinated by their GP who should invite the young person for an annual health check from age 14 and over. This can be supported by a number of services outlined below.

The exception is children in special schools; where young people stay until the July after they are 19.

#### **Hospital Consultants**

Young people may be under a variety of hospital consultants for example cardiology, neurology, ophthalmology, general paediatrics, orthopaedics, respiratory or others. These specialists will decide if transition needs to occur to an equivalent adult service. This will be between 16-18 years of age. Some services do not have an adult equivalent for example ophthalmology where young people will then be managed by high street opticians.

If the young person is acutely unwell and needs to attend the Accident and Emergency after 16 years they should go to adult Accident and Emergency department, but for children known to paediatric services already this usually 18 years.

#### **Palliative Care**

Similarly to children's palliative care services, adult palliative care can provide a personalised service to people living with a life limiting condition. They are an advisory service who does not have allocated inpatient beds, they help with support of complex symptom management, chronic pain, advanced care plans, rapid

discharges at end of life and signposting to other services. Adult services are based both at the North Bristol Trust (Southmead Hospital) and University hospital Bristol and Weston (UHBW).

## **Hospice Care**

**Charlton Farm** provides hospice support for children/ young people and their families unto the age of 21 years and accepts new referrals until the age of 16 years.

**Jack's Place** is a young person's hospice based in Hampshire and is the only one of its' kind in the South of England. It is a provision for young people living in the south of England and accepts referrals of young people aged 16 and above directly from families or professionals. The criteria for acceptance are that life expectancy should not exceed 35 years. This hospice provides respite care in addition to symptom management and end of life stays. It is young person focused and stays are exclusively for the young person.

**St Peter's Hospice** provides care for people living in and around Bristol with a life limiting illness. It provides a whole range of services both inpatient and outpatient including community nurses, a hospital at home service, a 24/7 advice helpline (available for professionals and families on 0117 9159430) and drop in support service. Inpatient provision is for symptom management and end of life care. There is currently no respite provision.

Being under the care of one hospice does not exclude you from being under a second. It is recommended that young people are referred to St Peter's hospice even if they do not currently require active care this allows the hospice to be aware of the young person in case care is required in the future.

## **Learning Disability Team**

Both North Bristol NHS Trust and UHBW has an allocated learning disability team who support medical care for inpatients and outpatients and admission planning for people with a diagnosed learning disability including autism. This includes ensuring a family member can stay with the young person whilst they are an inpatient if needed.

An overview of Southmead's services can be seen at the following link

<http://youtu.be/ytthEKCCqsY>

Further information can be obtained from the UHBW team on: 0117 342 1707 or the North Bristol trust team on 0117 414 1239.

With consent, we can forward young person details to the UHBW learning disability team – they will then ensure a flag is placed on the young person's online medical record to ensure that a learning disability team referral is made for any admission.

## **Multi professional Team**

If ongoing care is occurring under physiotherapy, dietician, speech and language therapy or occupational therapy then referrals will be made from within the team to their adult equivalent.

## **‘All about Me‘ Documentation**

It is helpful to keep an up to date concise printed folder of information about the young person including an up to date **hospital passport/ All about me document, advanced care plan (Wishes document in children known as RESPECT paperwork in adults) , medication list** (including doses) as well as the most recent **clinic letters** this could be brought to hospital attendances. Information is not automatically shared between services so doing this will prevent a lot of repetition and help to ensure the wishes of the young person and family are known.

- When a young person leaves paediatric services the upkeep of a hospital passport becomes the responsibility of the young person and their family. Any changes can be made on line by downloading the passport from:

<http://www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients/hospitalpassport/>

## **Financial Support is available**

At aged 17 year 6 months a young person should undergo a needs assessment by social care. This will determine if financial support should come from social care or health. Your family should speak to social services to arrange this or can do so online at [www.gov.uk](http://www.gov.uk)

**Direct payments** is a services for users to pay directly for their own care. You are entitled to this is you are 16 years or over and entitled to a community care service, you have parental responsibility for a child under 16 or you are carer to a young person aged 16 or over and an assessment has decided you are entitled to a carers service.

**Personal independence payment** replaces Disability living allowance at aged 16.

**Carers allowance** can continue to be granted

## **Blue badge**

These payments/ services should be applied for online the [www.gov.uk](http://www.gov.uk) website

If you need any help competing any of these application please contact citizens advice bureau or look on the website [www.carersuk.org](http://www.carersuk.org) for further information.

## **Education**

Further education is available for young people up until the age of 25 years. Talk to your child schools advisor for further information post 19 years.

## **Ethical considerations**

At 16 years or over the young person will have a mental capacity assessment to decide if they have capacity to consent to their medical care. It is encouraged for a young person to have autonomy and to encourage independence skills as much as possible.

Parental responsibility ends at 18 years and after this care is provided for the young person on a best interests basis for children who lack capacity to give valid consent to treatment. Those who have capacity can make choices around their medical care.

If the young person does not have capacity then a 'deputyship' can be applied for to allocate parents to have the ability to consent, a further option is to apply for lasting power of attorney.

## **Additional Information**

Young adults will not be under the care of a specific hospital trust- admission will depend on the location and needs of the young person at the time and families should be aware this could be to either hospital.

Other resources that may be helpful include:

<http://www.myadultstillmychild.co.uk>

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

<http://cchp.nhs.uk/cchp/explore-cchp/child-health-disability-services/preparing-adulthood>