

Transition

A time of change

A guide for parents, carers & families



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What is transition?

What is transition?

Transition can be viewed as any time in life when change occurs to one's relationships, routines and life roles. For a teenager, the transition into adulthood is an important time in life; however, it presents particular challenges for youth with an acquired brain injury. Young people may face numerous barriers in achieving independence and they often need support from family and the community to make a successful transition into the adult world. Part of this transition involves the shift from using child-based services to those that are adult orientated.

Why do we need to transition?

As your young person becomes an adult it is no longer developmentally appropriate for them to continue accessing the children's hospital and services. Let's face it ... the environment is designed for little children and young people may start to feel uncomfortable with this. In addition, the health professionals in these services specialise in children and so young people need to move to a service that can provide more specialised adult services to meet their needs.

What is the process involved?

During the last few years of attending paediatric rehabilitation services, steps will be taken to slowly work with you and your family to prepare for this change. This process may involve:

- » The young person spending time alone with their health professional to practice the skills they need to communicate with their health care team
- » Discussing the development of skills required for independent living
- » Working with all the service providers involved in your young person's care, who are also involved in assisting young people become young adults. This may include schools and local therapy services
- » Identifying and helping you connect with services available to provide support to your young person once they have finished with children services
- » Providing you with emotional support during this time of change.

For more information on this transition process, contact QPRS on 3068 2950.

Where do I now access help?

Over the next few years, the support needs of your young person will vary and may not be just health related. Some potential services that might be of help include:

- » General Practitioner: for all medical concerns. They will then be able to direct you to an appropriate specialist if required
- » National Disability Insurance Scheme (NDIS)
- » Community Health Centre: for physiotherapy, occupational therapy, dietetics, social worker services, speech and language pathology, podiatry and nursing
- » Centrelink: for financial concerns
- » Employment agencies: for assistance in gaining employment. If eligible for NDIS, include employment support in your plan.
- » Lifestyle support agencies: for social and recreational participation. If eligible for NDIS, include recreation and socialisation support in your plan.
- » Carers Queensland: for support for you as the carer. If your son/daughter is eligible for NDIS, you can request that they are provided with support worker hours or attendance at a group activity program to participate in everyday life. This will, in turn provide you with some respite.
- » Specialist non-government organizations e.g. Synapse, Spinal Care

Some families find that they start to rely less on formal services and start to develop support networks that can provide information and assistance as required. These informal supports can include:

- » Extended family members
- » Family friends
- » Connections made at local sporting clubs
- » Connections made with community support networks (e.g. carers associations and brain injury support groups)
- » Religious organisations.

If your young person requires ongoing specialised medical care, we will support a referral to the adult health services and assist you to transfer your medical records to this service. We will also talk with you about the available services.

Sometimes, it can be hard to know where to start looking for services to help you when a situation arises. We recommend that you contact Synapse (see below) in these situations.

Synapse

Synapse has a Community Response Service for all issues relating to acquired brain injury. All calls are answered by a Community Response Officer who will listen to the concerns of the caller, discuss the types of assistance or information that may be appropriate, and facilitate ways the caller can access the required support. All calls will be dealt with in strict confidence and the privacy of the caller will be maintained at all times. The caller does not have to identify themselves.

Contact details:

Level 1/262 Montague Road, West End,
Brisbane QLD 4101

Tel: +61 7 3137 7400 | 1800 673 074 (outside Brisbane)

Email: info@synapse.org.au

www.synapse.org.au

Spinal Life Australia

Spinal Life Australia is a provider of advocacy, therapy and supports for people with spinal cord injuries. Because of our position, we can also support people with other physical disabilities affecting their chosen lifestyle.

Contact details:

109 Logan Road
Woolloongabba QLD 4102

Tel: 1300774625

Email: enquiries@spinal.com.au

www.spinal.com.au/services/allied-health

Support schemes and concession cards

Companion card

This is designed for people with a disability who require an attendant for care support to participate in community activities. Attendant care support includes significant assistance with mobility, communication or self-care. It is not for simply company or reassurance. It promotes fair ticketing for people who need this level of support by removing the financial barrier of the costs of additional tickets for the carer when accessing community events.

Department of Communities | Tel: 13 74 68

www.communities.qld.gov.au/communityservices/community-support/queensland-companion-card

(Enter 'companion card' into the site's search tool)

Taxi subsidy schemes

The Taxi subsidy scheme entitles the applicant to a subsidy of half the total taxi fare, up to a maximum subsidy of A\$25.00. To be eligible for membership of the taxi subsidy scheme, you must fully meet at least one of the eligibility criteria listed below:

- » Physical disability requiring dependence on a wheelchair for all mobility outside the home
- » Severe ambulatory problem that cannot functionally be improved and restricts walking to an extremely limited distance
- » Total loss of vision or severe visual impairment (both eyes)
- » Severe and uncontrollable epilepsy with seizures involving loss of consciousness
- » Intellectual impairment or dementia resulting in the need to be accompanied by another person at all times for travel on public transport
- » Severe emotional and/or behaviour disorders with a level of disorganisation resulting in the need to be accompanied by another person at all times for travel on public transport.

Queensland Government: Transport and Main Road | Tel: 1300 134 755

www.tmr.qld.gov.au/Business-industry/Taxi-and-limousine/Taxi-subsidy-scheme-and-Vision-Impairment-Travel-Pass.aspx

Parking permits

There is now an Australia-wide disability parking permit that can be used anywhere in the nation. The disability parking permits are issued to people who have significant walking difficulties resulting from a medical condition or disability. The previous Queensland state scheme has been replaced and the previously issued blue permits are no longer valid. Under this new scheme, permits are no longer issued based on intellectual, psychiatric, cognitive or sensory impairments. For applications and further information, contact the Department of Transport and Main Roads customer service centre on 07 3834 2011.

Airline concession

QANTAS carer concession cards are distributed through NICAN. The carer concession card allows clients to have a carer with them on the plane for their trip. The carer concession card is only applicable to those clients that require a carer with them at all times during a flight. The concession card is not available to clients who only require assistance in embarking and disembarking a plane.

Visit www.qld.gov.au/disability for more informatino on the above schemes.

NDIS



What is it?

The National Disability Insurance Scheme (NDIS) provides eligible people with supports so that they can participate in the daily life activities they need to do, want to do or have to do.

Who is eligible?

Your teen may be eligible to apply if they have an impairment or condition that is likely to be permanent and that affects their ability to take part in everyday activities. The impairment needs to be severe enough to substantially:

- » reduce their ability to participate effectively or
- » reduce their ability to perform tasks without assistance from another person or equipment.

You will need to demonstrate that your teen's impairment affects their capacity for social and economic participation (work) and they are likely to require support for their lifetime (ie not a temporary problem).

Visit www.ndis.gov.au/ndis-access-checklist and complete the Checklist to help you know if your teen is eligible.

What type of information is needed when applying for the NDIS?

You will be asked to include a letter, assessment or report from a health or educational professional that details the impairment AND how this impacts on your teen's everyday life. If you do not have a current report then you can take the application form to a professional and ask them to complete it.

What type of information is needed when applying for the NDIS?

- » help for self-care and activities of daily living e.g. preparing meals, shopping, showering
- » transport to community, social, work and daily life activities (if you are unable to drive or catch public transport)
- » help to apply for and get a job or keep a job
- » therapies to help learn new skills
- » support to access recreation and social activities
- » help with household tasks so that you can live independently
- » provision of equipment including prescription, set-up and training
- » home modification, design and installation
- » mobility equipment e.g. wheelchair, walker
- » vehicle modifications and costs incurred to attain a license.

What will not be funded?

A support will not be funded if it:

- » is not related to the disability
- » duplicates a support your teen is already receiving via another system e.g. Medicare or Centrelink
- » relates to day to day living costs that are not related to your teen's support needs (e.g. clothing, food)
- » is likely to cause harm or pose a risk to others.

What are your teen's needs?

Some examples are:

- » Splints or orthotics
- » Mobility aids-eg wheelchair, walker
- » Daily living aids e.g. shower chair, kettle holder
- » Communication equipment
- » Help to look after my money
- » Help to catch public transport
- » Modifications to a vehicle
- » Help to find a job
- » Help to attend uni



The NDIS planning process

Step 1:

Think about your **needs** and **goals**

Step 2:

Meet with your planner

Step 3:

Develop your plan and manage your supports

Step 4:

Approve your plan

Step 5:

Review your plan

What are goals?

Goals can be short-term or long-term. Examples include:

- » I want to get a job
- » I want to go to Uni
- » I want to go to the footy
- » I want to stay fit
- » I want to go dancing
- » I want to live on my own or share with others
- » I want to travel
- » I want to go shopping on my own
- » Help to attend uni

Transition for Teens with Acquired Brain Injury

Acquired brain injury (ABI) is often referred to as the ‘hidden disability’. Many of the problems people with ABI face are not visible or do not appear to be that serious. Physical issues can be obvious, yet it is often the ‘unseen’ changes to the way a person thinks that can pose the greatest difficulties. There is generally a lack of understanding about the consequences of brain injury and the number of people affected within the community.

As your young person moves out of the school environment, they may experience issues that arise due to the general community’s lack of understanding of acquired brain injury. Sometimes people with a brain injury are assumed lazy or just difficult to get along with. As a result, the difficulties people with brain injuries face are easily overlooked or misunderstood and people are often left unsupported and isolated.

As a caregiver of a person with a brain injury, you may have to continue to express and advocate for your young person’s needs to the community. Self-advocacy is also a skill that you may try to encourage with your young person. For further support on self-advocacy and information to assist educating the community, you can contact Synapse.

Acquired brain injury and behaviour: Is it brain-injury-related or typical teenagers?

A common question family members often have is: does my young person act this way because he or she has had a brain injury or because he or she is a teenager?

After a brain injury, people may often experience decreased:

- » motivation to do things
- » initiation to do things—needing constant support to get started
- » insight into their abilities—thinking that they are more capable than they are
- » judgement—poor evaluation of risks in situations or a decreased understanding of how decisions will affect others
- » social and communication skills.

As you can see from the list, these behaviours often reflect those commonly seen within a teenager. Therefore, it might be said that young people act this way both because they are teenagers and because they have a brain injury.

Parents will also often ask if their young person will ‘grow out of it’. In some circumstances, the young person will. Often, young people with a brain injury do develop skills and abilities similar to their peers but often just take a little longer to do this. However, for some young people, these behaviours are the direct result of their brain injury and therefore although they may show some improvement in these areas, these issues may never resolve.

If some of these issues are of particular concern for your young person and it is affecting their lives and those of your family, it is recommended that you talk to a health professional about these. You can access support by talking with your NDIS planner about how the behaviours impact on your teens everyday life and ability to progress with other goals. For example getting a job, able to go to community functions.

If you have concerns about your teen’s ability to make decisions or their insight into their problems you can consider requesting a capacity assessment (see page 26, Impaired decision-making).

Disclosure and brain injury

Knowing who and when to tell someone about their brain injury can sometimes be challenging for people. Sometimes young people do not realise that everyone does not need to know about their personal information, and other times they might be too private and do not tell the right people who can help them participate more within the community.

There may be some benefits to letting an employer or tertiary education service know as it will:

- » enable supports to be provided to help them learn new things
- » help to avoid misunderstandings
- » help to educate others regarding the impact head injuries have on people
- » allow changes to be made in the workplace so that they can do what you need to do.

Changes that can be made in a workplace or high education program may include:

- » being flexible with expectations to match their fatigue levels
- » obtaining equipment to help them with physical tasks
- » writing things down so that they can remember.

Some people worry about disclosure because they fear they may be:

- » discriminated against
- » denied opportunities
- » denied certain entitlements
- » pitied by others
- » or that it might impact upon their privacy.

Disclosure is a personal choice; however, young people may need some guidance when making this decision. To help your young person think this through, a great help is the 'Choosing Your Path, Disclosure: It's a Personal Decision' program, which is available at: www.westernsydney.edu.au/choosingyourpath

For further information:

Talk to your child's occupational therapist or neuropsychologist at the Queensland Paediatric Rehabilitation Service.

You can also request support for employment/higher education via the NDIS.

For advice on how to disclose to an employer, see <http://jobaccess.gov.au>

For legal information if you are concerned about discrimination, see www.legalaid.qld.gov.au

Mental health

Ups and downs are a normal part of life. Teenagers in particular have wide swings of mood as they learn to deal with increasing independence and a changing body. This is to be expected; it is a normal part of growing up, though it can often be demanding to live with.

However, sometimes changes in behaviour are the first sign of something more serious. Many children with Acquired Brain Injury (ABI) can remember how they were before the injury, and adjusting to the changes can be very difficult. Changed abilities, disrupted schooling, and loss of friendships can cause great unhappiness, and young people often become depressed as they gradually become aware of the full impact of their ABI.

If depression is severe or prolonged, it can interfere with a young person's normal development and increase the risk that they will harm themselves in some way. Anyone with depression of this nature (whether or not they have ABI) needs treatment for their depression—and depression can be successfully treated.

The young person may find it helpful to talk about what he or she is experiencing. Sometimes it is easier to talk to a friend or professional rather than a family member.

ABI may cause problems with thinking and speech that make it harder to talk through problems, so it is particularly important to teach concrete ways to help the young person cope. However, even if speech and thinking are limited, the young person can often communicate their sadness and distress. It is important to listen to what your young person is saying rather than how he or she is saying it—simply having someone listen and care is a help.

Can acquired brain injury lead to mental illness?

Mental disorders can occur in anyone, and are common in our society. Most disorders do not have a single cause, but result from a complex combination of events and conditions, including the person's biological and inherited make-up, their psychological make-up and skills, and their family, social and community environment. Risk factors such as stress increase the likelihood that a person will develop a mental disorder.

Conversely, protective factors help people to cope with adversity such as an easy temperament, a strong and supportive family and school environment, and a sense of belonging. Adolescence—particularly later adolescence—is the time when mental disorders are at their most common.

Many young people with ABI will not develop a mental disorder, but some inevitably will. Each young person's level of risk and protective factors will be different, but some of the effects of ABI do increase the risk of some mental disorders. For example, ABI can erode a young person's confidence and self-esteem, and behavioral problems can put teenagers and young adults at high risk of becoming socially isolated and without friends.

Symptoms of a mental illness

Parents are the people most likely to notice signs of a mental illness or emotional disorder. The signs can be difficult to identify, as many resemble the effects of ABI. They include:

- » rigidity in thinking and behaviour
- » unwarranted worry or anxiety and inability to cope with day-to-day problems
- » changes in sleeping or eating habits
- » aggression (verbal or physical) towards others
- » excessive fear and feelings of persecution, paranoia
- » recurrent nightmares and seeing, hearing or experiencing things that are not there
- » depression or social withdrawal
- » difficulty 'getting going'.

What to do

If you are concerned about your young person's mental health, it is important that you seek help. This can be from:

- » your GP who can refer your teen for 6 to 10 sessions with a psychologist; can be funded by Medicare (there will be some gap in cost) under a GP Mental Health Treatment Plan
- » psychiatrist - you will require a referral from your GP
- » counsellor, psychologist or social worker.
- » The Emotional Health unit at Mater Young Adult Health Centre. This service provides access to professionals in psychiatry, psychology and social work. Medicare rebates are available for patients who have a GP Mental Health Plan or referral from a psychiatrist or paediatrician. You can access psychology or social work without a referral but will not then get a rebate.

Tel: 07 3163 6102

Web: www.materonline.org.au/services/mater-young-adult-health-service/emotional-health-unit

For further information

Lifeline

www.lifeline.org.au

Tel: 13 11 14

Beyond Blue

www.beyondblue.org.au

Tel: 1300 22 4636

Kids Helpline

Tel: 1800 55 1800

ReachOut (online mental health organisation for young people and their parents)

au.reachout.com

Balancing risk and independence

Growing up involves taking risks—this is normal as young people ‘test the waters’ and move towards independence and adulthood. Risks are of many types. Some are social, for example, inviting someone on a date for the first time; and some are emotional, such as talking about fears. The risks that most concern parents are usually those that might cause physical harm. Sometimes young people do dangerous things deliberately; sometimes they just do not see the risks.

One of the important things parents do is to help young people learn to manage and judge risk. This may involve them learning what the outcomes of some risk-taking behaviours are and learning how to respond in the event that the risk becomes dangerous. Parents who encourage independence and allow a manageable element of risk are showing optimism and confidence in their young person.

Decisions about risk crop up all the time—your young person may want to go to the shops alone, go to a party or socialise with people you do not know, go to nightclubs, and even learn to drive. Ask yourself:

- » Does he or she have the necessary skills?
- » Can I trust him or her to follow the rules?
- » What are the likely risks, including risks to others?
- » Are there dangers outside his or her control?
- » What would make it safe?

It may be tempting to put physical safety above all else, but saying ‘no’ too often can have a cost. Young people lose confidence, rebel or simply miss out.

Brain impairment and risk

The pitfalls and dilemmas faced by all parents can be magnified when the young person has a brain impairment. The young person may be less capable of anticipating danger, judging risk, or showing self-control. It may be harder to learn the skills needed to be safely independent. These might be physical skills, and/or skills related to behaviour, judgement, memory and perception.

Impulsive behaviour can place the young person at risk. Loss of confidence, self-esteem and friendship networks may make the young person more susceptible to the influence of peer groups, as he or she tries to impress, fit in, and make friends.

At the same time, if you try to protect your young person by restricting them more than others of their age, this can also affect their self-esteem and relationships with other young people.

What protects young people from risk?

Research has shown that some of the most important factors that protect young people from becoming involved in some of the riskier activities include:

- » a strong and caring family
- » a sense of connection to family
- » open lines of communication
- » a pro-active approach to solving problems
- » having a good relationship with an adult outside the family—someone who believes in the young person.

Managing risks

It is always important to equip young people with the skills, knowledge and confidence to say 'no' to things they do not want to do. At the same time, risky activities are a normal part of growing up, and it is imperative to try to minimise any harm that may result.

Where a brain impairment is present, there are further considerations. For example:

- » Can the young person understand and remember instructions, rules or laws and apply general rules to specific situations?
- » Are impulsivity and poor judgement an issue?
- » What sort of training or instruction does the young person need to maximise the chances that he or she will act responsibly and safely?

The following strategies may help:

- » Set sensible and firm limits based on your family's values and respect for laws and regulations.
- » Be a good example and role model.
- » Try to keep the communication lines open within the family—listen to what your children have to say, and respect their point of view (even if you do not agree with it).
- » Provide a 'safety net' of appropriate supervision—be aware of their friendships, know where they are at night, and be awake when they get home.

If you have concerns:

- » Address with the NDIS planner - request support for your teen to do the activities they are wanting to do, but with supports to ensure safety.
- » Consider Capacity assessment and/or referral to adult guardian (see section on impaired decision making).
- » Talk with GP- request psychology support.

Caring for yourself

Caring for a loved one can be a 24-hour a day task, which can be demanding both physically and emotionally. Most carers will say that sometimes they feel overwhelmed and unable to cope, and have doubts about how they will.

To ensure your young person is well looked after, it is important that you care for yourself.

The first step may be asking yourself some health-related questions:

- » Are you getting enough rest/sleep?
- » Are you eating regular meals?
- » Are you getting regular exercise?
- » Do you have regular times for relaxation and leisure?
- » Do you have someone you trust to talk to about how you feel?

Respite

Respite refers to some ways of getting a break from the role of carer to allow you to attend to your own needs and re-energise for the ongoing care of your young person. It involves services providing care of your young person while you take a break. This can occur in your own home, in centres set up for this purpose or while your young person is supported to participate in community activities.

Commonwealth Respite and Carelink Centre can provide:

- » information on respite services available
- » support services available for carers
- » referral to appropriate service providers
- » respite in emergency, short-term or planned care situations
- » emotional support.

When you are feeling overwhelmed, it may be helpful to talk with a person who listens and may be able to guide and assist. These people could include:

- » family, friends, GP
- » services such as:

Commonwealth Respite and Carelink Centre

Tel: 1800 052 222

www.commcarelink.health.gov.au

Queensland Carers Australia

Tel: 1800242636

www.carersqld.asn.au

Carer Gateway

Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The Interactive service finder helps carers connect to local support services.

www.carergateway.gov.au

Is respite covered by the NDIS?

With the roll out of the NDIS, comes lots of change and with change can often come confusion. One area that is cause for some confusion is respite care. When asking for respite type support it is important that the focus of the request remains on your son/daughter and how receiving this support can help them achieve their goals. For example, receiving respite type support may assist your teen to become more independent, increase social skills, or access activities outside of the home.

If deemed eligible, your teen may be able to receive respite type supports such as in-home, out-of-home and overnight respite as part of their NDIS plan.

There is currently no item in the price guide specifically for “respite”. Regardless, respite is available but the NDIA uses different terms which you may not be familiar with. These include:

- » assistance with daily living (support with self-care activities)
- » assistance with Social and Community Participation
- » short-term accommodation and assistance (overnight respite).

How do I get respite type supports for my son/daughter?

As with all of the supports that you request as part of your first NDIS plan, your request for supports provided by Support Workers will need to be deemed as “reasonable and necessary” by your NDIA Planner. So be prepared to justify why this care is reasonable and necessary for your teen and your family.

Grief: A response to children growing up

What is grief?

Grief is our response to loss. It is the normal, natural and inevitable response to loss, and it can affect every part of our life, but it is varied and different for different people. We may experience intense feelings such as sadness, anger, anxiety, disbelief, panic, relief or even numbness. Sometimes, grief can cause difficulty in sleeping and can lead to physical symptoms. If these symptoms persist, check with your doctor to exclude other causes.

A child growing up

As a child grows older, some parents experience a sense of loss as they realise that their child is changing into a young adult. Some parents may find this a confusing time because there is a sense of sadness about how life is going to change but, conversely, there is a sense of excitement about the future.

For parents of young people with a head injury, this sense of loss maybe complicated by:

- » feelings of intense protectiveness for the young person because they have been so reliant on parents as they have recovered
- » young person not being able to fulfil some of the hopes and dreams they had due to the head injury.

As a young person becomes an adult, there are many things within society that change, not just for the young person but also for the family. Some of these include:

- » loss of connection with schools and teachers who have been supportive over the years
- » loss of connection to other support services (such as hospitals and therapy services) who no longer can support young people when they turn 18
- » loss of control and ultimate decision making regarding where the young person goes, what they spend their time doing and who they spend their time with.

Grief is a very normal response to loss or change, but sometimes it can feel a little overwhelming. In these situations, it might be useful to talk with someone about your feelings. This could be a trusted friend, a social worker, counsellor or your General Practitioner.

For further information, see www.grief.org.au

Helping your young person take responsibility for his or her own health

Now that your son or daughter is becoming an adult, it might be time to start encouraging them to take more responsibility for his or her own health. Things that you can encourage your young person to do include:

- » taking responsibility for taking their own medication at the right times, with less prompting from you. Ask if they know what the medication is for, what doses they have and get them to tell you when the script needs filling
- » getting them to fill the script as needed—they might need to see you do this a few times before they can do it themselves
- » scheduling appointments with the doctors—if they are sick and need to go to the GP, get them to find the number of the GP and be with them as they make a call to ask for an appointment
- » going to part of the medical appointment by themselves—this makes them less reliant on you telling the doctor what has been happening. They might need to talk with you about what to say before they go in and get them to write it down if you think they will forget
- » let them take the responsibility for following the doctor’s instructions—encourage them to write the instructions down to help them remember what to do
- » get them to look after their health equipment. They should know how to clean them, and who to contact if they get broken
- » MY HEALTH RECORD: online summary of your health information; you control what goes into your record and who is allowed to access it. This is now an opt-out service. That is, you inform your GP if you do not want it. If you opt-out it might be helpful to keep all of their health information in the one place at home.

A balanced lifestyle

Maintaining good health is important so that they can do the things in life they want to do. Therefore, it is important to encourage your young person to have a balanced health lifestyle. Some important tips are outlined below.

Eat well

Eating well is important because food supplies the energy nutrients that our bodies need to work and stay healthy. Unhealthy eating may lead to serious long-term health problems. Some helpful suggestions include:

- » Maintain a balanced diet: lots of fruit and vegetables and less fat and sugar.
- » Drink plenty of water—do not wait to you are thirsty. Try to drink about two litres each day.
- » If you would like your teen to improve their diet you can organize for them to see a dietician who can help them explore healthy food choices.

Rest

Our bodies and minds need rest to recover and re-energise. If they do not get enough rest, then they might find:

- » their thoughts go slower
- » it is difficult to make good decisions
- » muscles do not work as well and you become more clumsy.

Some tips for getting enough rest may include:

- » take a break when tired
- » maintain a good sleep pattern—wake up and go to bed at a regular time
- » do not do anything too energetic just before bed
- » reduce screen time (TV, Computer, IPAD, electronic games) in evenings
- » dealing with things that are worrying you.

Get out and about

Leisure

All work and no play is not a good idea either. It is all about balance. It is important to remember:

- » make time for friends
- » find a hobby or leisure activity you enjoy doing. It is a good idea to try a few different things to find one that really suits you.

Exercise

Exercise is important in keeping your body fit, especially if your teen has spasticity or muscle weakness. For more suggestions on this, visit www.healthier.qld.gov.au. If your teen requires support or special supervision/training, then include this in your NDIS plan.

Work

It is a good idea for people to do things that are important to them that involves them in the community. This can be paid employment, volunteer work or just being involved in a local community group. Work can also be those things that they do to help around the home, such as chores (see page 40, Helping your young person choose a career).

Steps to helping your teen with health and lifestyle

- » Teach them organizational skills such as using a diary, reminders on phone, calendar etc.
- » Be a role model- they will benefit from seeing you attending to your health, keeping fit, socializing and having a balanced lifestyle.
- » Show them how you manage everyday routines/responsibilities eg budgeting, planning a holiday, organizing for repairs to be done etc.
- » Teach them to look for services/find information.
- » Have expectations that they will contribute to household. That is, do some chores, pay board, help with cooking.

Health professionals

Your son or daughter will have had contact with many health professional as they were growing up. It is typical however, that they tend not to know which health professional has the knowledge to help them with what issue. Here are a list of some of the professionals that they might need in the future and what services they might be able to provide.

General Practitioner

A General Practitioner, often known as a GP, is the local doctor who people go to see when they are feeling sick or have a question about their health. It is a good idea to encourage your young person to visit their doctor at least once a year for a check-up, even if they are feeling well, to maintain a good relationship with them. GPs will also be the starting place for a referral to any medical specialist they may need in the future. For example, if they develop a concern about their heart, they can recommend (refer) them to a heart specialist. If they need some support for their mental health, they will be able to recommend (refer) them to a psychologist.

Your GP can plan and coordinate the healthcare of patients with chronic conditions (e.g. ABI, Spinal Cord injury, Cerebral Palsy) including patients with conditions who require multidisciplinary, team based care from a GP and other care providers via the Chronic Disease Management program (part of Medicare).

Optometrist

An optometrist examines people's eyes for vision problems and sells glasses or contact lenses to correct them. If they already have glasses, they should have their eyes checked every 12 months to two years. If they do not have glasses, then they should see an optometrist if:

- » they have blurry vision either with objects up close or far away
- » their eyes start to have tears or watery eyes
- » they have spots, strings or flashes of light in their sight.

Most optometrists bulk bill, which means that they do not have to pay for their eye test. There will be a cost for the glasses if they need them, but if they have private health insurance, then the cost of glasses is less.

Optometrists can be found at your local shopping centre, by Googling optometrists in your local area, or by looking up the Yellow Pages. Once they have chosen one, call to make an appointment and take your Medicare care with them.

In some situations, your young person may have been regularly reviewed by an ophthalmologist. When your young person turns 18, they should explain to you if these reviews need to continue. If they do, then they will organise a referral to an adult ophthalmologist.

Occupational Therapist

An Occupational Therapist (OT) can assist your teen with acquiring adult skills required for everyday life such as self-cares, work related skills, hand function, organizational skills, and independence skills such as shopping, budgeting, catching public transport. Accessing an Occupational Therapist:

- » see your GP to access Medicare funded sessions (limited number)
- » private health insurance
- » Request OT in your NDIS plan (will need to justify it is required to help your teen to achieve their goals).

Finding an OT:

www.otaus.com.au/find-an-occupational-therapist

Psychologists

Psychologists assist people with everyday problems such as stress and relationship difficulties, and some specialise in treating people with a mental illness such as depression, anxiety or psychosis. They help people to develop the skills needed to function better. Psychologists cannot prescribe medication. Their treatments are based on changing behaviour and emotional responses without medication. Accessing psychology services:

- » ask your GP - they can refer for a limited number of Medicare funded sessions (up to 10 sessions)
- » search the 'find a psychologist' webpage on the internet:
www.psychology.org.au/FindaPsychologist/
- » include psychology service in your NDIS plan. You will need to justify that the sessions will assist your teen with attaining skills in order to carry out activities they want or need to do; for example able to cope with anxiety in order to get a job.

Physiotherapist

Physiotherapists treat patients with physical difficulties resulting from illness or injury. Physiotherapists work with people to improve their movement and function, and reduce pain. It might be a good idea to see a physiotherapist if your young person experiences:

- » pain in their muscles or joints (back, neck, shoulder, arm, hip, knee, leg, foot)
- » an injury to their muscles when playing sport
- » difficulty moving and stretching a joint (knee, ankle, hip) because their muscles are tight.

If your son/daughter has significant tone problems check with the physiotherapist that they have expertise in neurological conditions. Accessing a physiotherapist:

- » GP - medicare will assist with funding limited number of sessions per year
- » private health insurance
- » NDIS - if you can link physiotherapy with functional goals such as mobilizing in the community, being independent in the home, participating in work
- » search the 'find a physiotherapist' webpage on the internet:
www.physiotherapy.asn.au/APAWCM/Controls/FindaPhysio.aspx

Dietician

Dieticians provide advice and education on healthy eating habits to treat specific illnesses and to promote general health and wellbeing. They can work with your teen to make changes to their diet to help achieve a healthy weight and well-balanced diet, manage food allergies or intolerances, advise on specialised tube feeds or manage any other diet-related issues.

It is a good idea to see a dietician if they are having trouble losing or gaining weight, are receiving tube feeds, if they need to restrict certain foods from their diet, or if they just need some good advice about eating and drinking well.

To see a dietician in the public system, your teen will generally require a referral from their medical specialist in the hospital. They can also see a dietician in the private system by talking to their GP, or visiting the Dietician Association of Australia website to find a dietician in the local area (www.daa.asn.au).

You may be able to justify NDIS funding for a dietician/nutritionist by explaining that this service will contribute to attaining everyday goals e.g. healthy weight will promote self-confidence and fitness for work.

Multidisciplinary services/units

Mater Young Adult Health Centre (MYAHC)- for young people aged 16 to 25 who require following specialists: Craniofacial, Cystic Fibrosis, Diabetes, Gastroenterology, gynaecology (13 to 18 years), respiratory, rheumatology and urology. If accessing any of the above outpatient services, the patient is eligible to also access the various educational and social programs on offer. No fee with Medicare card.

Web: www.mater.org.au/Home/Services/Mater-Young-Adult-Health-Centre-Brisbane/Our-Services

There are some rehabilitation services at private hospitals. Gold Coast private Hospital, Buderim Private Hospital, Check with your health care fund in respect to rebates.

Rehabilitation specialists - Adults

In adult health care there are Rehabilitation Specialists employed in public hospitals that have rehabilitation services. The criteria to access their outpatient services are dependent on each health service district.

If you have private health care, you may wish to access a private rehabilitation specialist. The following web page has them listed with information on the doctor's specialty area (eg spasticity management, neurology, pain)

Web: www.healthshare.com.au/directory/rehabilitation-medicine-physicians-in-brisbane-4000-qld/

Talking with doctors and other health professionals

For some young people, talking with professionals about their health can be a little overwhelming. Here is a process that you can talk about with your young person that might assist them. It is called the 'GLAD' principle, which stands for Give, Listen, Ask, Decide, Do. This tells the young person what they should do and talk about when visiting a doctor. The young person should:

Give

- » information about how they are feeling
- » information about what they have done to help themselves
- » information about their past history if it is not known
- » information about how their everyday life is being affected (a health diary might be helpful)
- » honest answers.

Listen

- » to what the people tell them about the condition and how they can reduce the effect it has on their life.

Ask

- » any questions they have about their health (it may help to write these down before they see the doctor/health professional so they do not forget any important questions they may have)
- » if they don't understand something the doctor has said. Sometimes, doctors use unusual words or speak too quickly, so the young person may have to ask them to explain it again in a different way. These are some useful examples of what they could say to a doctor/health professional if they have not understood everything:

Please tell me more about that?

Could you explain that to me again?

Could you write that down for me?

Is there something you can give me to read?

Decide

- » what they want to achieve with their health. They should get involved in making decisions about how they want their health care to be managed
- » at their appointment what they need to do next

Do

- » their part in following the action plan
- » be a useful member of their health care team

Things for families to be aware of when moving to adult health services

The move to adult services is often complicated because these services operate a little differently than children services do. However, once people know how they work, families tend to manage the change fine.

Differences in the adult services to be aware of:

- » Adult health services tend not to perform regular reviews just to check to see how things are going. They tend to be very focused on function and only see you when a concern arises. They are not able to provide maintenance therapy within the public system—you will have to seek private fee for service agencies for this.
- » Adult services expect the young person to initiate and drive the health care process. They expect a certain level of self-motivation and compliance with therapy program. If the young person is only there because their parents tell them they have to, and they do not implement the strategies at home, then chances are the young person will be ‘discharged’ prior to achieving the goal.
- » Adult services are short term, goal focused and are often time limited. Without a goal, there is no service.
- » If your young person forgets an appointment, adult services require that you contact them to reschedule this appointment. They will not be automatically rescheduled.
- » Adult health services are usually reactive not proactive—they see you once the problem arises.
- » There is less coordination of adult health services: whereas you might have been able to see all your doctors and therapist at the children’s hospital, in adult services, you might have to see different professionals at different locations. There is often no one central person you can talk to about your concerns and therefore your young person will have to talk and coordinate things with a variety of different people.
- » Changes in the role of the family member—in adult services, families are not excluded from care but the priority and direction is usually taken from the young person.
- » Financial considerations: there are often less subsidies provided for equipment/consumables for adults.
- » Waiting lists: there are usually longer waiting lists for adult support services than you may have experienced within the children service.

Adult health services are very experienced and want to partner with your young person to address issues that impact on their ability to participate within the community.

Consent and confidentiality about health issues

As young people age, they are encouraged to become more active decision makers in their health care. However, to consent to medical treatment, one must be capable of forming sound and reasoned judgments. Once a person turns 16, it is generally assumed by the law that one has full capacity to consent, if the treating medical team are confident that the person understands the treatment and its consequences. Parents can only agree to or refuse medical treatment on one's behalf if they are not able to make their own decisions. In this case, the decision must be made in the person's best interests. Young people are able to include their parents in their health decisions at any time. Parents also may still be involved in the consultation but the doctors will expect that the young person will start to speak for themselves during the appointment.

At times, young people also may wish to discuss medical concerns with their doctor without their parents or caregivers being aware of the nature of their concerns. In these situations, a doctor can only decide to disclose their confidential health information if they believe:

- » that the young person is not able to understand the decisions they are making
- » they consider it to be in their best interests.

In these situations, they could disclose confidential health information to people who have an interest in the young person's health like a parent or guardian. The law says that doctors (and sometimes nurses) must report certain things like thoughts of suicide, infectious diseases or when they think someone is at risk of serious harm.

Refer to the next section to further understand what you can do if your teen needs help with understanding medical information and therefore may not have capacity to make decisions on their own.

Impaired decision-making capacity

The law recognises everyone's right to control his or her own life. People are presumed to have the capacity to make decisions for themselves unless their incapacity is established.

Incapacity in decision making is referred to as 'impaired decision-making capacity'. Capacity has three components:

- » Understand: An individual must be able to understand the nature and effect of a decision.
- » Decide: An individual must be able to come to a decision freely and voluntarily.
- » Communicate: An individual must be able to communicate that decision to others.

Clearly, someone who is in a persistent vegetative state or a coma has impaired capacity. A person who is unable to communicate in a coherent manner due to a fine-motor coordination deficit or cognitive deficit also has impaired capacity.

It is important to note that simply making decisions that you perceive to be 'bad' does not imply impaired capacity, and making decisions that are potentially harmful does not imply impaired capacity—every individual has the right to make decisions that may result in physical, financial, psychological or other harm. This is referred to as the 'dignity of risk'. A consistent pattern of decisions that result in harm to the person or their quality of life may suggest that there is impaired capacity.

Queensland Civil and Administrative Tribunal

The Queensland Civil and Administrative Tribunal (QCAT) provides a legal mechanism for ruling if an adult has impaired capacity, and providing for a guardian or administrator to make decisions on their behalf. The Tribunal has authority to appoint or unappoint guardians and administrators, and to set the limits of the authority of guardians and administrators.

The Tribunal also gives directions and advice to guardians and administrators and has the authority to monitor orders and register orders made in other States and some other countries. The Tribunal also gives consent for special health care.

Guardians

A guardian is someone appointed by the Tribunal to deal with the day-to-day personal decisions of an adult with impaired decision-making capacity. Guardians make decisions about personal but not financial matters. The authority of a guardian is determined by the Tribunal, and can be as specific or as broad as the Tribunal considers appropriate. Examples of guardianship orders include:

- » suitable accommodation after the person in question leaves hospital and until accommodation is secured, at which point the order lapses
- » all health-care decisions only
- » accommodation, social contact and service provision.

A guardian must be over eighteen years of age and not a paid carer or health provider for the person in question. Unpaid carers can be a guardian.

Administrators

An administrator is someone appointed by the Tribunal to make financial decisions on behalf of an adult with impaired capacity. The process of applying to be an administrator is quite complex as the Tribunal demands a high standard of applicants—in essence, the process of application requires that a business plan be drawn up to cover expected future costs.

Administrators must be over the age of eighteen and not a paid carer or health provider for the person in question.

Office of the Adult Guardian (OAG)

Adult Guardian is the ‘guardian of last resort’. If the Tribunal decides that a guardian is needed for an individual, but there is no appropriate family member, friend or service provider who can take on that responsibility, then the OAG is appointed as Guardian.

The OAG has one very important additional responsibility: it has the power to investigate charges of abuse or neglect against an adult with impaired capacity. In this role, the OAG has the authority to require someone to provide records or information and to suspend an Enduring Power of Attorney for up to three months during the course of an investigation. The OAG can also apply to QCAT for a warrant to enter premises and remove an adult where there is suspected immediate risk to that adult.

Public Trustee Office of Queensland

The Public Trust Office is a self-funded State Government agency that provides Queenslanders with financial, trustee, legal, property and associated services. The Tribunal may appoint the Public Trustee Office of Queensland as administrator for an adult with impaired capacity if there is no appropriate individual close to the adult who will accept the responsibility, or if there is dispute over who should act as administrator. However, it is also possible for an individual to choose to put their financial affairs in the hands of the Public Trustee under their Disability and Aged Support program.

Powers of Attorney

An attorney is an individual who makes decisions on your behalf. An attorney may have the same authority as a guardian or an administrator, or both, or have specific authority to make decisions in areas that you decide.

More information on powers of attorney is available from the Office of the Adult Guardian.

Statutory Health Attorney

A Statutory Health Attorney is someone with automatic authority to make health care decisions on behalf of an adult whose ability to make decisions is permanently or temporarily impaired. A person assumes the role of statutory health attorney as a result of their relationship with the patient—for example, spouse or primary carer—and is not a formal arrangement. However, an enduring power of attorney, general power of attorney or advance health directive (see below) may have authority over a statutory health attorney. This role ends when the patient regains capacity; however, a statutory health attorney may make an application to become a guardian and/or attorney if the impairment appears to be permanent.

If you are acting as a statutory health attorney, it is a good idea to apply for guardianship as soon as it becomes clear that the impairment is likely to be permanent. Your status as statutory health attorney can be challenged, particularly if the decision-making capacity of the individual is in doubt. Your status as an appointed guardian can only be challenged at a QCAT hearing.

General Power of Attorney

A General Power of Attorney is a formal arrangement between yourself and another person that authorises that other person to make financial decisions on your behalf when you are absent, for example, overseas. It lasts for as long as you are absent.

The General Power of Attorney form is available on the website of the Department of Justice and Attorney General, Queensland.

Enduring Power of Attorney

An Enduring Power of Attorney is a formal arrangement between yourself and another person that authorises that other person to become your attorney in case you become incapacitated. It is a way of arranging guardianship and administration in advance, with a person whom you trust. The Enduring Power of Attorney can specify what

decisions your attorney will have authority over and can be as specific or as broad as a guardianship order is. Once the agreement comes into effect, decisions made by your attorney have the same legal force as if you had made them yourself.

The General Power of Attorney form is available on the website of the Department of Justice and Attorney General, Queensland.

Advance Health Directive

An advance health directive, also known as a 'living will', is a document that establishes your wishes regarding health care in the event of you becoming incapacitated. Anybody who is over the age of 18 and does not have a decision-making impairment may make an advance health directive.

A directive can include refusing treatment, including life-saving treatment. The directive only has power when the medical team is aware of its existence, so make sure that sympathetic family members or friends are aware that you have made a directive.

Please note: some people suggest that if you do not want to get resuscitated following a car accident or other serious injury, you should tattoo 'Do Not Resuscitate' across your chest. This is not worth the price of the ink. Only a complete, signed and witnessed Advance Health Directive form has legal authority.

The application form for a directive can be downloaded from the OAG website. Part of it needs to be completed by your GP and the form needs to be witnessed by a Justice of the Peace, Commissioner for Declarations, lawyer or Notary Public.

For further information:

Queensland Civil and Administrative Tribunal www.qcat.qld.gov.au

Tel: 1300 753 228

Office of the Adult Guardian www.justice.qld.gov.au/guardian/ag.htm

Tel: 1300 653 187

Public Trustee Office of Queensland www.pt.qld.gov.au/index.htm

Check the website or contact the head office on (07) 3213 9288 for contact information on an office in your area.

Thanks to Synapse for permission to adapt their material for this fact sheet.

Emerging sexuality (a parents guide)

Both surging hormones and the wish for a successful social life fuel teenagers' interest in sex. For parents, adolescence can be challenging. For young people, it is exciting and potentially risky. A brain impairment can increase these risks.

For example, where judgement, planning skills, social skills and self-esteem are all affected, a young person is at higher risk of unplanned pregnancy, sexually transmitted disease and sexual assault. These young people may be vulnerable to being exploited and manipulated, and sexual activity may be a response to feeling isolated. Impulsiveness can further increase the risk.

Reduced self-esteem and self-confidence, and decreased social skills, can affect a young person's ability to develop relationships and be accepted by others. In addition, some people with ABI, intellectual impairment or other disabilities may lose the normal inhibitions we place on our behaviour. They may do and say inappropriate things—for example, use sexually explicit language or masturbate in public—and this inevitably affects the way others relate to them.

Physical disability following brain injury can affect a young person's ability to engage in sexual or self-pleasuring activity, and an injury during adolescence—a time when acceptance by peers is so important—can have a devastating effect on self-image and self-esteem.

Sex education and guidance

To negotiate these years safely and successfully, all young people need to learn about their sexuality. They need to know how to avoid risks to their health and their social and emotional development, and find positive and healthy ways to express their sexuality.

The risks involved in sexual behaviour have changed over time. Unplanned pregnancies have decreased— but the risks of sexually transmitted disease, including HIV/AIDS, are real. Attitudes towards homosexuality are more positive—but young people can still feel shame, guilt and regret about their sexuality.

Having information is a good first step. It does not prevent all problems—adolescents are not always able to put theory into practice. However, research shows that teenagers who receive appropriate sex education tend to delay first intercourse, use contraception and avoid pregnancy. Of course, family input is crucial, too.

Like their peers, young people with a brain impairment need:

- » informal education, at all ages, on sex and self-care—such as having their questions answered by trusted adults
- » formal sex education, such as that provided by schools.

Young people with ABI, CP, Spinal cord injury and other disabilities may need extra time to absorb information and learn self-care, for example, managing monthly periods for a young woman. In addition, a young person with a disability affecting executive thinking (for example they have concrete thinking) may need to practise skills in a variety of specific situations—it may be very difficult for them to generalise from one situation to others.

Young people with learning or executive difficulties are also more likely to need very firm, clear guidelines about what is appropriate. A degree of tolerance is needed—if they do or say inappropriate things, shaming or punishment does not help. The issue needs to be dealt with quietly and firmly, without condemning the person.

Sometimes, a trusted adult or young person outside the immediate family is in a better position to provide information, support and advice.

For an extensive catalogue of information and services relating to relationships, sex, sexuality and sexual health when someone has a disability, contact your local Family Planning Association.

When young people are sexually active

Young people with cognitive, behavioral or executive impairment who are sexually active may be at risk because of poor judgement, planning and follow through, and/or of social awareness and skills. For example:

- » They may be less likely to use 'safe sex' methods to prevent infection or unwanted pregnancy.
- » They may be more likely to deny symptoms of infection.
- » If they have an infection, they may delay seeking treatment or not complete a course of treatment, especially if symptoms decrease.
- » They may not inform their sexual partners about any diagnosed infection they have.

These are difficult issues for parents to address at the same time as respecting their young person's privacy. You may be able to go with your young person to the doctor, or get a friend to go, or rehearse with the young person what they will say to the doctor.

For further information about discussing sexuality with young people, see www.true.org.au (Queensland) or the family planning association in your state. NDIS will fund family planning if you are part or wholly managing your plan.

If you feel your teen would benefit from some specific counselling around sexuality and relationships or requires support to participate in mainstream young adult activities safely (eg going to concerts, gigs, pubs) consider requesting support via NDIS (that is, discuss this goal with the planner).

Medicare supports

If they have not already done so, your young person can apply for a Medicare card of their own. They can do this by completing an application form (you can download one from internet or pick one up from your local Medicare office). They will also need to provide two forms of identification.

Medicare Safety Net

The Medicare Safety Net provides families and individuals with financial assistance for the out-of-pocket expenses associated with out-of-hospital medical services connected to the Medicare Benefits Schedule (MBS). Once you meet a Medicare Safety Net threshold, you may be eligible for additional Medicare benefits for out-of-hospital MBS services for the rest of the calendar year.

PBS Safety Net

What is the PBS Safety Net?

If your young person needs many medicines in a year, the Safety Net helps them with the cost of their medicines. Once they reach a Safety Net threshold, they can apply for a PBS Safety Net card—then their PBS medicine will be less expensive.

What do they need to do?

They need to keep a record of their PBS medicine on a Prescription Record Form (PRF), which you can get from the pharmacy. Each time they have a PBS medicine supplied, give the form to the pharmacist so it can be recorded. Once they have reached the threshold, they will be issued a card that will entitle them to reduced priced prescriptions.

For more information, see www.medicareaustralia.gov.au, or Tel: 132 011

Health Care Cards

If your young person is on a Centrelink payment, they may be eligible for a health care card. A Health Care Card entitles you to cheaper medicines under the Pharmaceutical Benefits Scheme (PBS) and various concessions from the Australian Government – these could include:

- » bulk billing for doctor's appointments (this is your doctor's decision)
- » more refunds for medical expenses through the Medicare Safety Net.

State and Territory Governments and local councils may offer concessions, such as:

- » energy and electricity bills
- » health care costs including ambulance, dental and eye care
- » public transport costs

For further information, contact Centrelink www.centrelink.gov.au

Private health insurance

In Australia, the public health system Medicare covers most Australian residents for health care. However, Medicare does not cover everything and so people can choose to take out private health insurance to give themselves more choice in health care.

Private health insurance requires people to pay a fee (premium) and in return, when they need to access health care, the insurance company will cover the cost of this. The amount that they cover differs depending on the health insurance company so always check beforehand.

There are two types of cover offered. The first is hospital cover, so if you require a hospital stay and procedure then this is covered. The second cover often referred to as extras cover is for all the therapy that can occur outside of the hospital. Each health insurer covers different therapies so it is best to talk with them to find out what they can do for you.

As parents, if you already have health insurance, your young person can be covered by this until they turn 21. If they are studying, they may cover them for longer. Please check with your insuring company.

How to obtain private health insurance

There are many different deals available so it is important to get the one that is right for your young person. Things to consider include:

- » What health services do they cover?
 - hospitals
 - therapies—what types, how much of each therapy will they cover (some services have a limit to the amount of therapy you are able to claim each year).
- » Will there be additional costs at the time of the health service?
 - Excess—the amount of money you pay and they will pay the remaining
 - Gap fee—the insurer will sometimes only pay a percentage of the cost of the therapy service and you will have to pay the rest.
- » How much is the premium (fee you pay)?

Some helpful tips

- » Help them write a list of what is important for them to have in their health insurance.
- » Help them to call at least three health insurance companies and talk with someone about whether what they can offer matches what you want.
- » Use a comparison website like iSelect to compare health insurance companies.

See www.privatehealth.gov.au/healthinsurance/

The seven basic health care rights

It is important when accessing health care that you and your young person are aware of your health rights and responsibilities. They are the same regardless of whether the service is for children or adults.

Your rights include:

- » **Access:** you have a right to access health care services to address your health care needs.
- » **Safety:** you have a right to receive safe, high-quality health services provided to you with professional care, skill and competence.
- » **Respect:** you have a right to be provided with care that shows respect to your culture, beliefs, values and personal characteristics.
- » **Communication:** you have the right to receive open, timely and appropriate communication about your health care in a way you can understand.
- » **Participation:** you have the right to join in making decisions and choices about your care and about health service planning.
- » **Privacy:** you have a right to the privacy and confidentiality of your personal information.
- » **Comment:** you have the right to comment on or complain about your care and have your concerns dealt with promptly and properly.

How you can help us help you

There are a number of things patients can do that will help the hospital to provide better care.

Information you should provide the hospital staff:

- » your medical history and any treatment or medication you were receiving when admitted to hospital
- » any changes in your condition
- » any special needs you have
- » if you are unwilling or unable to follow any treatment instructions
- » if you require more information.

Consideration for staff and other patients:

- » Try to keep your appointments. If unable to keep an appointment, advise the hospital as soon as possible.
- » Be aware and considerate of the needs of other patients.
- » Be courteous and respect the role of hospital staff.
- » Be aware that hospitals have a special role in the training of health care professionals. Therefore students or trainees may be present at appointments.

Encouraging independence

Now that your child is becoming an adult, they might like to start becoming more independent. We recognise that no one is fully independent, and that each person has a different capacity and relies on the help of friends and family to varying levels. This independence can take many forms, such as:

- » helping out around the house more
- » looking after their own needs, for example, making their own meals and snacks, taking their medication independently, doing their own first aid
- » going out with friends more frequently or without supervision
- » getting to and from school independently using public transport
- » spending time at home alone
- » for more disabled young people, it might be using a communication device, expressing discomfort, making choices, expressing goals.

We recognise that not all young people have the same skills and ability and that the highest possible level of independence is not the same for all people. Independence is not something developed overnight and is a gradual process whereby the young person is allowed the opportunity to try to learn new things. We have found that teenagers with a disability may need a little extra time to learn these ‘adult skills’ and therefore starting early, and giving them lots of opportunity to practice can be very helpful. Some other helpful tips that may encourage independence include:

- » start talking about the future early with young people
- » encourage them to make decisions by offering them choices
- » teach the young person how to get their voice heard—encourage them to do the talk for themselves but be there as back-up if required
- » allow opportunities for the young person to explore their interests and abilities
- » encourage them to take more responsibility around the house and for their own health care
- » decide as a family what areas of independence you want to focus on developing – do not try everything at once
- » clearly discuss with your young person the expectations you have of them if you allow them more independence.

Remember, it may not always be possible for you to be there to care for your young person so intensely, so by teaching them these independence skills, they are more likely to get by and participate within their community. Sometimes, it is not possible for the families to provide the intense training that some young people need to learn basic life skills. In these situations, community organisations provide living skills programs for young people post-school, which provides this experience and education.

For some young people, it is never going to be possible for them to be independent and they will need support for most activities for the remainder of their life. In these situations, a young person can be encouraged to develop and communication skills (may need to be via a device) to make some choices, express basic needs and desires and to learn how to direct carers respectfully.

How to obtain supports for your teenagerto learn independence skills

- » Apply to NDIS and set goals with the planner. If eligible for NDIS you can request the provision of therapy, support workers, devices, modifications , transport support, attendance to group programs etc to assist your teen to work on independence skills.
- » Centrelink has a Skills for Education and Employment program that my help to improve speaking, reading, writing or math skills. Go to: www.humanservices.gov.au/individuals/services/centrelink/skills-education-and-employment

Accommodation

It is a big decision regarding whether your young person should move out of home. It can often create a variety of emotions within parents.

Questions that may assist this process include:

- » Do they want to live out of home?
- » Can they afford to live out of home?
- » What types of accommodation options are available and which might best suit them?
- » What location would suit them?
- » Do they have the skills to be able to live out of home independently or will they need someone to support them?
- » Can they cook and clean up after themselves?
- » Do they know how to access help when needed?
- » Can they pay their bills?
- » Can they shop?
- » Can they get themselves out and about?

Accommodation options

Living with family

If your young person is keen to move out of home, but it is not currently realistic for them to do this independently, having their own living area (eg create a 'granny' flat) or living with other family members (older sibling who has moved out of home, or an aunt or uncle) might be a first step in the process. Some potential benefits might include:

- » less financial burden on the young person
- » an environment that can encourage greater independence, with people who understand if they do not always achieve success
- » reassurance for the parents that there is a supportive adult available to the young person.

Share housing

This is a cheaper option of independent living whereby a group of people share the rental and utility costs of a house or unit. This group of people can be known to your young person (a group of friends) or people who they have not before. Share housing options can be found in your local newspaper, local community notice boards or websites such as www.gumtree.com.au or www.realestate.com.au

Government housing

State and federal governments across Australia provide some housing that is commonly known as government housing or public housing. These houses are usually one, two or three bedroom and are provided in order of need or what is called 'priority'. There are certain eligibility criteria such as having a disability or being a low-income earner. Some of these houses can be or have already been modified for disability access. There are often waiting lists for this accommodation (possibly years long depending on the location for which you wish to apply) and therefore it is recommended that you consider this in your planning process. For further information, you can access the Department of Communities website: <http://www.communities.qld.gov.au/housing>.

Supports funded by the NDIS

The NDIS will assist participants to live independently. This includes:

- » Supports that build his/her capacity to live independently in the community, supports to improve living skills, money and household management, social and communication skills and behavioural management.
- » Home modifications to the participant's own home or a private rental property and on a case-by-case basis in social housing.
- » Support with personal care, such as assistance with showering and dressing.
- » Help around the home where the participant is unable to undertake these tasks due to their disability, such as assistance with cleaning and laundry.

Special Disability Accommodation (SDA)

- » NDIS will assist with Specialist Disability Accommodation (SDA) for people with high needs.
- » SDA provides funding towards the cost of the physical environment- limit of five to one building.
- » SDA homes may range from apartment to free standing house.
- » It is important to note that SDA does not cater for all people with a disability-it only caters for those that need a specialist housing solution.

If your son/daughter is assessed as requiring funding in their plan for SDA support and need assistance to find a home, the NDIS will help you. That means that during the planning process you undertake with the NDIS, support hours will be included to facilitate finding accommodation and will include information about what SDA is available in your area.

Supports funded by housing and other systems

Most Non-SDA housing remains the responsibility of state and territory governments. For more information contact the housing authority in your state or territory. They are responsible for:

- » Social and community housing. There are certain eligibility criteria such as having a disability or being a low-income earner. Some of these houses can be or have already been modified for disability access. There are often waiting lists for this accommodation (possibly years long depending on the location for which you wish to apply).
- » Homelessness and emergency accommodation services.
- » Commonwealth Rent Assistance, a payment through the Department of Human Services that assists eligible participants with the cost of housing.
- » The National Rental Affordability Scheme (NRAS) that is creating additional affordable rental properties.

Private rentals

If over the age of 18, your young person might be able to sign a lease on a private rental. Private rentals can be more expensive, but you are given more choice regarding the location and the style of house or unit.

The properties available for private rent can be located via local real estate agents, www.realestate.com.au and www.domain.com.au.

For more information regarding the responsibilities of rental agreement, you can contact the Residential tenancies authority on 1300366311 or visit their website: www.rta.qld.gov.au

Helping teenagers learn to manage their money

An important step in gaining independence is being able to safely manage your money.

Money management must be learned and practiced. Consider teaching the following habits in everyday home and family life to better prepare your young person for 'real' life.

- » Discuss with your young person the difference between needs and wants. As basic as it sounds, many financial difficulties could be avoided if people understood that it is merely impossible to have everything you want, and that some things are more important than others.
- » Help a child understand there is no such thing as things for free. If a young person wants an item, help them earn and save money to purchase it without going into debt.
- » Teach the value of working for money, whether by getting a job or by doing extra chores around the house.
- » Include your young person in the process of making a family monthly budget. Make a list of all your income. Then, ask them to come up with a list of expenses, including rent or mortgage, food, insurance, car payments and maintenance, clothing, and so on.
- » Resist the urge to rescue your young person. Stick to what you have stated about wants verses needs. This may become difficult while surrounded by other shoppers, but it will teach your young person a great deal about money and control, which will help them avoid unnecessary debt in the future.
- » Give your young person advice, but allow them to make their own decisions—good or bad. Young people will learn the most from personal experience, perhaps especially mistakes.
- » Saving is an important habit to begin early but it helps to have a goal to work towards.
- » While grocery shopping, show your young person how to comparison shop, pointing out ways to maximise your dollar, such as reading price labels for price per kilo, or using junk mail to plan your shopping list.
- » Give your young person the opportunity to hand money to cashiers, bank tellers etc.

If you are concerned about your young person's ability to manage their money some helpful service may include:

- » Centrelink: they have a service called Centrepay that pay some bills automatically before issuing the remaining benefit to the young person. See www.humanservices.gov.au/individuals/subjects/managing-your-money-day-day
- » Public Trust can manage finances for the young person, providing them only with a small income while ensuring bills are paid. See www.pt.qld.gov.au
- » This webpage gives you information about which bank accounts do not incur fees for being overdrawn or prevent this happening: www.finder.com.au/bank-accounts-no-overdrawn-fees

Helping your young person catch public transport

Being able to get safely from point A to point B is a part of being independent. To make the transition from child to independent adult easier to do, it is a good idea to start teaching the skills needed to use public transportation when the person is in high school.

School buses

A good way to introduce the use of public transportation is to teach your young person how to ride the school bus. Using the school bus is a great way to learn how to find a bus stop, how to wait for a bus, how to get on a bus, and how to get off the bus.

Reading schedules

The next step in teaching your young person about public transportation is learning how to read a schedule and how to find where you need to go. This is a very complicated task to learn so you will need to break it up into smaller lessons. You can start by learning how to read a schedule or how to look this up online. Then you can teach your young person how to select the right bus route to take to get to a specific place such as their grandparents' house, the library or their own house.

Riding public transport with a parent

Step three will be to ride the bus or train with a parent. Encourage the young person to help select the right bus, to get on the bus, to pay for their bus fare, and to know when to get off the bus.

Trying it alone

Once they are familiar with the route, your young person might be able to try the route independently. For some people, it might be helpful to have further practice steps that involve having someone meet with them either end of the trip.

Other tips

- » If young people have mobile phones with data on it, they can look up timetables and journey planners when they are out and about.
- » Young people can also call Translink to get step-by-step journey information.
 - » Include transport training in your **NDIS** plan.

Voting

When your young person turns 18, they will be required to enrol to vote. Voting is the formal process whereby Australians can choose who they want represent them in Federal, State and Local Government.

Enrolling to Vote

It is a requirement of law to enrol and vote in elections if you are an Australian citizen over the age of 18. Failure to do this might result in penalty. Enrolling will require your young person to complete a form and return it to the Australian electrical commission.

If your young person is unable to sign their name due to a physical disability, they may get you or someone else to complete their enrolment form and sign it on their behalf. To complete the enrolment for this way, they will need a registered medical practitioner to complete and sign the medical certificate on this form.

People do not have to enrol and vote if they:

- » are not 18 years of age or over
- » are of unsound mind (incapable of understanding the nature and significance of voting)
- » currently in prison
- » are a permanent resident but not an Australian citizen.

If you are unsure whether your young person has the capacity to understand the significance of voting, you can discuss this further with your health professional. You may also refer to the section in this information package regarding decision-making capacity.

How to vote

For more information regarding how to vote, an online training package has been compiled by the Australian Electoral Commission and can be found at:

www.aec.gov.au/Voting/How_to_vote/voting_practice.htm

For further information, contact:

Australian Electoral Commission

www.aec.gov.au

Tel: 132326

Helping your young person choose a career

Finishing high school and deciding on what to do next is a challenging time for most young people. For most young people, they are just focusing on completing Year 12 and looking forward to a holiday when they finish. Schools often vary in how much they discuss options for young people when they finish Year 12.

Young people's career decisions are often influenced by a range of factors, including family, teachers, careers specialists, contacts with employers, perception of a subject, money, and their own values and interests.

Things to consider when choosing a career path:

- » Will this career require further study, is the young person willing/capable to do this study?
- » What are the young person's strengths and weaknesses and how does this reflect in possible career choices?
- » Where is the future headed—what are the opportunities for this career in the job market?

Family members

Family are found to be particularly influential in providing first-hand knowledge of jobs and work. Family members are often well placed to understand the young person's strengths and weaknesses and can therefore encourage work options that focus on their strengths.

Work experience

Research has shown that contact with employers provided useful inside information regarding different jobs and work environments. Work experience has the capacity to affect career decisions either by reinforcing choices, suggesting new possibilities, or leading to rejection of an earlier career choice.

Professional assistance

Schools are often happy to sit with young people to discuss post school options. There are also professional career counsellors and psychologist that can assist in this process. During your final years at QPRS, you would also have had the option of discussing this with your health professionals.

Online activities

There are often online checklists that you can use to help young people identify their strengths and weaknesses and identify employment areas of interest.

See www.myfuture.edu.au/

Work experience

What is work experience?

- » It is the chance to gain hands-on experience of the types of jobs your young person is considering.
- » It allows them to see and join in the everyday activities of a workplace.
- » It can often be a helpful first step towards finding a job.
- » It is usually unpaid and is set up for a defined period.
- » It allows them to see if they are suited to that type of work.
- » It gives them experience to put on their resume.

How do I get work experience?

- » This can sometimes be organised through the school. Talk with the guidance officer about this.
- » If you have finished school, employment agencies can assist in making the contacts with employers.
- » They can also do it themselves. Find the company they wish to do work experience with and contact them. For more information on how to do this, you can look up www.workexperiencedirectory.com.au/work-experience-ideas/but-what-should-i-do

How do I decide what to do?

- » make a list of things that they might like to do when they finished school
- » talk with other people—find out what they have tried
- » talk with the school guidance counsellor
- » talk with QPRS transition coordinator about options.

For further information:

www.myfuture.edu.au/

Part-time employment

Some young people want to work while they are still at school. Some benefits of having a part time job include:

- » earning money
- » gaining experience to help get a job when you finish school
- » meeting new people
- » learning job readiness skills such as following directions, being on time.

Some parents express concern regarding this because they are worried about:

- » how will it impact on their school learning
- » how they will be able to get there
- » if they are ready for this level of responsibility
- » if employers will understand about the impact the head injury has had on their young person.

If you have concerns regarding this, it might be helpful to talk with the health professionals at QPRS or your local service provider about this.

Getting a job

There are many ways that young people can go about getting a part-time job. First, they have to decide what type of job they want, for example:

1. Hospitality –often they will not need experience to find a job as a kitchen-hand, dishwasher or waiter. It is worth looking at any local restaurants and cafes.
2. Retail – it can be very useful to spend a day at a shopping centre asking around supermarkets and other stores whether they need anyone.
3. Fast food – most of the time, no experience is required and these can be a good starting point as a first job.
4. Mail runs – delivering mail can be a fun way to exercise while earning some money, without the pressures of working with lots of people.

Employment agencies

Employment agencies are places that help connect people looking for jobs with the right employer. They can help people:

- » choose the type of job to best match what you like doing
- » help develop résumé and interviewing skills
- » assist people make that contact with the employers.

Some employment agencies specialise in helping people with disability –like people with brain injuries or Cerebral Palsy – get jobs.

Applying for Jobs

Many employers now have on-line application systems whereby they will request specific information. Some may request a resume to be attached. For helpful tips on creating good résumés, they can talk with their guidance officer or careers counsellor at school. Alternatively, there are many helpful websites available including the job seekers and employees section at <http://jobaccess.gov.au/JobSeekers/Pages/home.aspx> Tel: 1800 464 800.

Employment supports

An employment agency is an organisation that assist people find a job. They can support people at all stages of the process, from identifying the type of work to apply for, gaining training for career choices, creating résumés, interviewing skills and connecting people to employers.

People who have a brain injury or other disability often require more support in the job application process and can benefit from support once within the workplace to accommodate for some of the issues that might arise as a result of their disability. In these situations, it is often better to access specialised employment services.

Disability Employment Services

Disability Employment Services (DES) provides specialist help for people with disability, injury or health condition who require support to find and maintain sustainable employment. If you are seeking a referral to DES, you should get in touch with Centrelink or visit your local DES provider.

Eligibility: Most participants with disability, injury or health condition will be assessed by a Job Capacity Assessment (JCA) or an Employment Services Assessment (ESAt) to determine their eligibility for DES. For young people leaving high school, they may be able to skip the job capacity assessment and go directly to the DES provider. For a job seeker to access a DES, they must be assessed as having a future work capacity of at least eight hours per week.

There are two programs within DES:

1. Disability Management Service

Provides help to people with disability, injury or health condition who require the assistance of a disability employment service and are not expected to need long-term or regular support in the workplace.

2. Employment Support Service

Assists people with permanent disability that are likely to need regular long-term ongoing support in order to retain their job.

Finding a provider

There are many providers available. To find one in your local area, visit <http://jobsearch.gov.au>

For further information or to find out about your eligibility for DES, phone Centrelink on 131021.

NDIS funded employment services

NDIS will fund supports to assist young people with employment where these are beyond the requirements of employers and employment agencies, such as:

- » Assisting young people who are not eligible for DES (Disability employment services, see above) or Job Services Australia (JSA) to build skills and capacity in employment as well as assistance to find and keep a job. Building capacity means developing such skills as communication skills, emotional regulation, transport skills etc.
- » Personal care or assistance with transport.
- » Assistive technology such as wheelchair, communication device, hearing aide.
- » Supported employment such as services offered by Australian Disability Enterprises.

The **School Leaver Employment Supports (SLES)** is an NDIS early intervention approach for school leavers (year 12 students) with a significant disability. It supports their transition from school to employment. The aim of SLES is to build a participant's capacity to meet the access criteria and transition to a DES. A SLES participant may need up to two years to develop the aspiration, confidence and sufficient skills to meet DES criteria. Planners consider the aims of SLES along with the participant's goals and circumstances (reasonable and necessary support) to determine whether SLES would be beneficial for the individual.

Employment services



Visit: <https://jobsearch.gov.au/serviceproviders-to-explore-job-search-agencies/support-services>

Jobactive: is for most people looking for work.

DES: Disability Management services is for people who have a disability, illness or injury who need occasional support to find and keep a job

DES: Employment Support Service is for people who have a permanent disability, illness or injury. It gives you long-term, regular ongoing support to find and keep a job

Transition to Work: TtW is for young people aged 15 to 21 who need to build skills and confidence to get a job.

Studying after high school

Studying at TAFE or university is often very different than studying within a supportive school environment and can be a little overwhelming for young people. Choosing a TAFE or university can be an important step.

Some things to consider when choosing a TAFE or university are:

- » Do they offer the courses that your young person is interested in?
- » What are the entry requirements for these courses and does my young person meet these?
- » What is the campus layout like—can they access their classrooms (consider impact of fatigue as well as physical access)?
- » What supports do they offer young people with disabilities?
- » What are the financial costs of doing further study?

It is often helpful to research the TAFE or university prior to application deadlines. Most educational facilities have a websites or open days that you can attend. In most instances, considerations for courses needs to occur before September each year; however, young people have many opportunities in which to change their minds and alter their preferences.

Disability Service Officers

While at high school, your young person may have had some support from teachers to help them learn and complete assessments. Some of this support may also be offered through the TAFE or university they wish to enrol in. This can be accessed through the Disability Service Officers (DSO) found at the student services at the TAFE or university.

What they do

DSOs provide information and assistance to students with a disability. Although they may not see their head injury as a disability, the law states that if you have a head injury that you are entitled to receive support services.

DSOs work collaboratively with students to identify their support requirements. This means that they can have a say in how they want to be supported. The DSOs will not know your young person's history therefore will need to be informed about how the head injury has affected their ability to learn. They can use their medical reports from QPRS to help with this process. It is best to get this support early—they can always decrease the amount of support given but sometimes it is too late to obtain help after the assessments are finished.

Ways they can help

- » provide and physical equipment for your young person to access the classrooms
- » provide some changes to the course based on the 'reasonable adjustment' concept.

What is reasonable adjustment?

The ways DSO can help are ruled by what is called 'reasonable adjustment'. This basically states that they cannot provide special advantages to anyone (people will still have to sit the exams and prove that they can do what the subject is teaching) but they can make some changes so that your young person can have the same opportunities as other people doing the course (give more time to complete exams).

How to contact DSOs

An appointment can be made with the disability support officers by contacting student support services at your specific TAFE or university. Please refer to their website for contact details.

Long-term future

The future will always hold some degree of uncertainty and sometimes things happen unexpectedly. Some families feel more comfortable if they have thought through and made plans for when these things may happen.

Some questions you may like to consider and possibly talk through with may include:

- » How much care will my young person require after they become an adult?
- » Who is available to care for my young person if they are unable to care for themselves?
- » What are the financial considerations regarding the level of care my young person may need during adulthood?

The answers to these questions are different for every person depending on:

- » your cultural and family beliefs
- » resources available to the young person.

Services that may be able to assist you plan for the future include:

- » lawyers and legal aid – to advise how to legally provide a plan for unexpected events. www.legalaid.qld.gov.au or 1300 651 188
- » Department of Communities: Disability and Community Services – to provide information support and referral to care providers who provide support. They may also be able to provide potential financial support in some situations. See www.communities.qld.gov.au, Tel: 1800 177 120 or contact your local customer service office.

