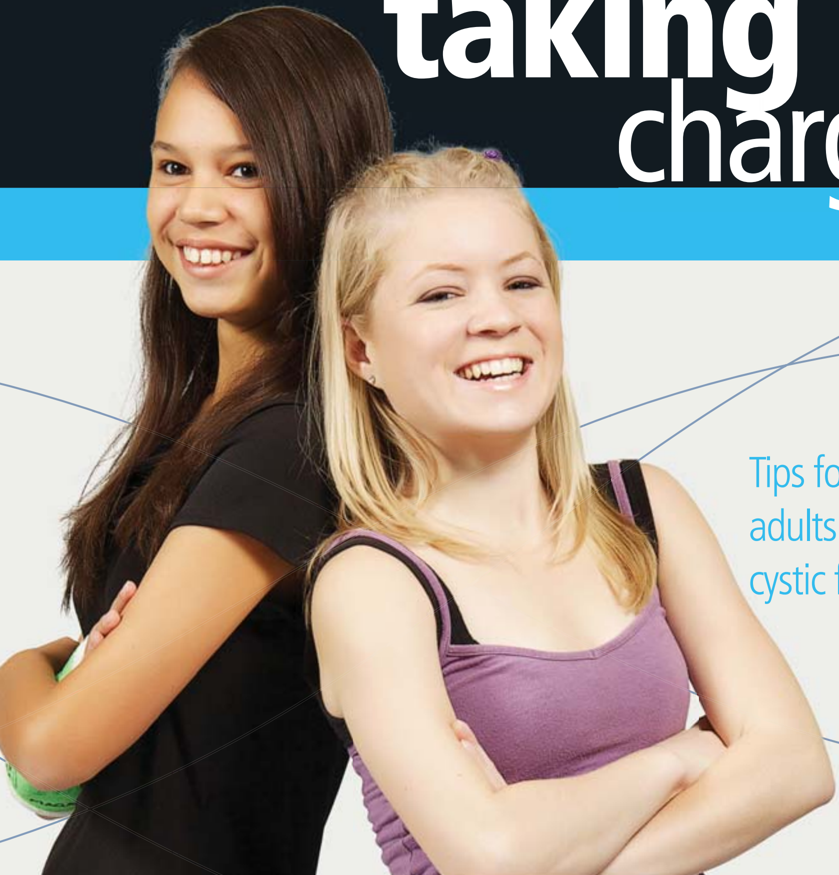
transition pack
moving to adult care

Cystic Fibrosis Western Australia

Supporting young adults to transition from paediatric services to adult care

taking charge



Tips for young adults living with cystic fibrosis

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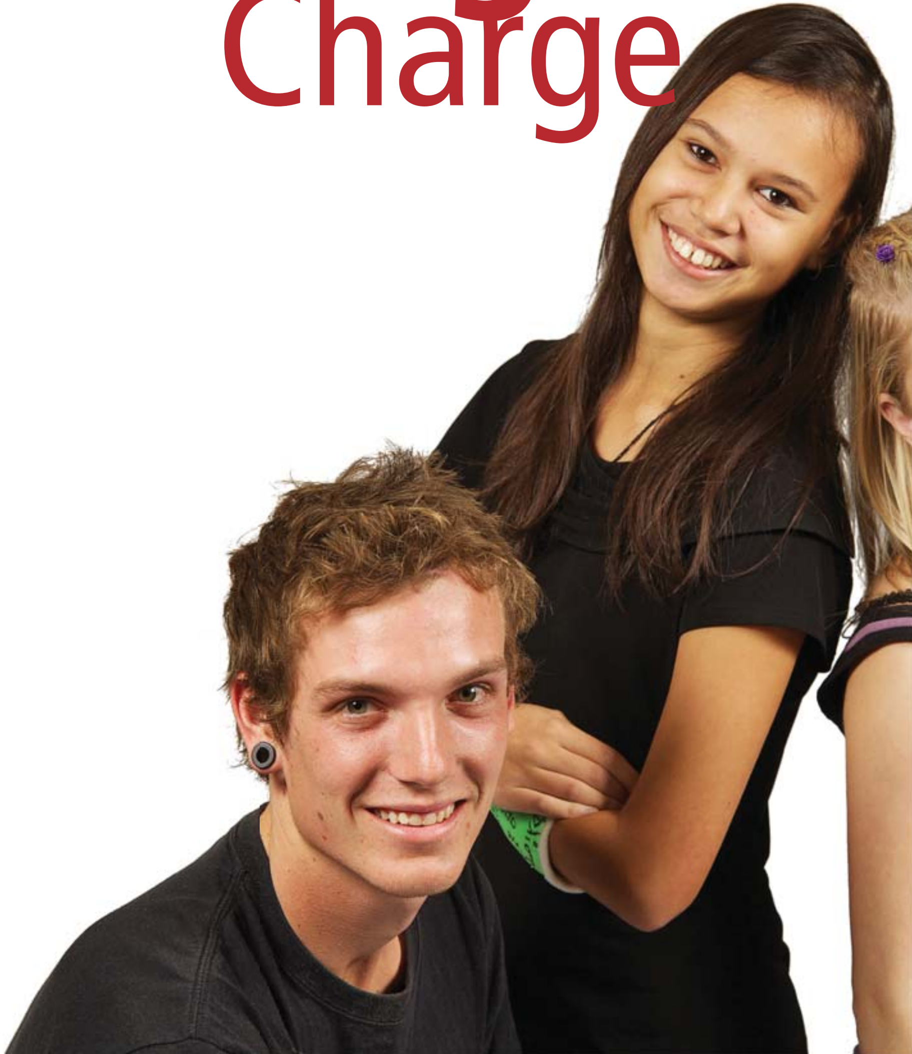
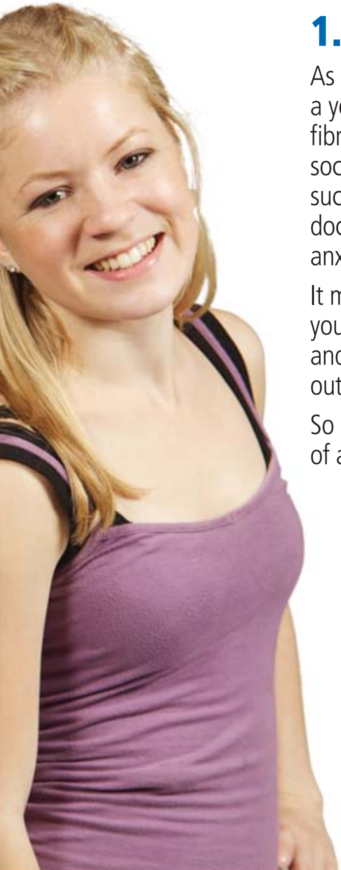


Congratulations! You have reached the beginning of adulthood. It is a very exciting time when you can vote, drink legally and start to make big decisions about what you want to do with your life. The aim of this booklet is not for you to sit down and read it all at once, but to have a look now and then at the bits that might concern you during your initial journey into adulthood.



1. Introduction

As well as facing all the highs and lows and challenges of being a young adult, you have the extra challenge of living with cystic fibrosis. This may affect you not only physically, but also emotionally, socially and financially. This booklet provides hints and tips for topics such as living independently, living with your parents, talking to doctors and medical staff, standing up for yourself and dealing with anxiety or depression.

It may take time to accept the realities of a long-term illness, but young adults who learn about their illness, seek support from others, and participate actively in the care of their body have more positive outcomes.

So best of luck to you as you navigate through the twists and turns of adulthood and enjoy TAKING CHARGE!

2. What can Cystic Fibrosis Western Australia Do For You?

You will have started the transition process from Princess Margaret Hospital (PMH) to Sir Charles Gairdner Hospital (SCGH)and may have met your team of clinicians. Cystic Fibrosis Western Australia (CFWA) also has a team of people available to assist you if the need arises.

Our Services Team is made up of the following:

A CFWA Community Nurse who hires out travel nebulisers, carries out home visits to flush ports, changes PICC line dressings, takes blood (if unable to attend pathology centre) as well as providing simple lung function tests. The nurse also takes people transitioning from PMH to SCGH on a tour of SCGH and regularly visits patients with CF in hospital to discuss any issues.

Homecare workers are carers who assist with airway clearance and exercise programs in the home. They can also assist with light household duties after a person has had a transplant.

A CFWA Physiotherapist who works with the homecare workers to assist with a person's airway clearance and exercise needs at home, in consultation with the physiotherapy at SCGH. The CFWA physiotherapist is also a useful person to consult if you are having motivational issues in regards to doing physiotherapy and exercise.

A Social Worker who can assist with issues arising from Centrelink, the Health Care Card, Mobility Allowance and other allowances, and can provide one to one counselling and support on a variety of issues.

An Education and Recreation Officer who can provide education about cystic fibrosis to individuals or groups, in the community, families and in work places. The education and recreation officer can also assist with preparing for employment i.e. updating your resume, helping you write a job application or organise work experience at CFWA, if appropriate.

A Project Officer also provides education sessions, organises recreational events and the hospital goody bags.

The RED Room is a place that you are welcome to visit if you are staying at SCGH and need a change of scenery. You can watch DVDs, have a coffee , snacks, browse through some magazines, listen to music or use the computer. This place is a bit like a lounge room with a great selection of interesting books and DVDs (not all of them CF -related).

The RED Room will be open between 9am and 5pm, Monday to Friday if you wish to pop in.

To avoid cross -infection and to check if the room is available, please contact either the office on 08 9346 7333 or 08 9346 7337 or email: educationofficer@cysticfibrosiswa.org

You can view our library catalogue online at: www.cfwalibrary.org.au

Hospital Survival Kits are still provided by CFWA once you have transitioned to SCGH and are admitted to the ward. The packs aim to provide useful materials during admissions including toiletries, high- fat snack foods and sugary soft drinks, food vouchers, a pen and notepad as well as things to alleviate boredom including magazines, puzzle books and information about CFWA events and news.

Equipment Loan the following items can be loaned from CFWA, in consultation with your physiotherapist at SCGH. To make inquiries contact either the CFWA Nurse nurse@cysticfibrosiswa.org or the CFWA Physiotherapist physio@cysticfibrosiswa.org

- Pari Boy mobile S with 12 volt for car charger, plug for USA, plug for Australia
- massage tables
- sports/exercise equipment grants
- Wii Fit games and Wii Console
- mini trampolines
- treadmills, exercise bikes
- boxing equipment and weights

CFWA Membership may have been through your parents, but once you turn 18 you will need to become a member in your own right to access our services free of charge. All you have to do is complete a membership form, which you can find online at http://www.cysticfibrosis.org.au/wa-about/wa-membership/ or we can post you one, or visit our office to fill one out.

3. Being the Boss of Your CF Treatment

Learn as much as you can about CF - get all the facts!

If you know about CF yourself, you will feel more in control. Organisations such as CFWA are available to assist with up- to -date resources and information about CF if needed. Talking to someone who is knowledgeable about CF can also be helpful to get a different perspective. It is good if you find someone who is approachable, can speak openly about the different aspects of CF and is also up- to- date with their information.

Due to cross- infection, CF can be a very isolating illness, however, the value of speaking to someone who knows exactly where you are coming from can reduce this feeling of isolation. If you follow the cross- infection rules of one metre distance, or use other forms of contact such as Face Book, e-mail or Skype, you can still interact with other people who have CF. CFWA can also put you in touch with other people who have CF who may be close to your own age and have similar interests.

Talking to doctors and other health professionals

You are probably quite used to interacting with a variety of medical practitioners and specialists. However, when it comes time to visit doctors on your own or to discuss issues you don’t want your parents to know about e.g. sex, drugs or depression, anxiety or incontinence it can be embarrassing and nerve- wracking. Not only do you have to consult with your CF medical team at SCGH, you also may need to discuss other health or emotional issues with your local GP. Being examined and questioned about your body can also be intimidating, especially when the doctor needs to examine you in places you have always considered private, such as your genitals or breasts.

To make things easier consider the following things about the doctors and medical professionals you will interact with as an adult

- Your doctor’s seen it before. Most experienced doctors have cared for hundreds or even thousands of patients, so chances are they’ve heard, seen, and even smelled just about everything before. No matter how troubling something might be to you, it probably won’t surprise your doctor.
- Your doctor is there to help, not judge or punish. Your doctor is interested in keeping you healthy, not judging you for something you have or haven’t done. For this reason, a person who is concerned about a sensitive topic, such as

having an STD, shouldn't avoid going to the doctor because he or she is ashamed or worried about what the doctor might think. Not having things like STDs checked might only make a condition worse. A doctor's role is to listen respectfully, examine, educate, and treat people, not criticize them. If you think your doctor is judging or preaching to you, talk to your parents about finding someone with whom you're more comfortable.

- It's your job to talk openly about your symptoms and concerns. A doctor can't help you unless you tell the whole story. Even if you're uncomfortable, being open and honest will only benefit you. Most doctors realise that people can feel uncomfortable about raising sensitive issues and they try to be good listeners. Most doctors also realize that no one is perfect. Trying to manage your CF treatment, plus work, relationships, friends etc is tricky, so the team at SCGH will want to help you work your treatment around your life, not the other way around.

If you have several issues that you wish to address with your doctor, try showing up for your appointment with a written list. It can include your problems, symptoms, questions, and concerns. Many people find that once they've brought the subject up and gotten past those first nervous moments, they feel a lot more comfortable talking openly.

Managing your treatment

Now that you have transitioned to SCGH the onus is much more on you to manage your CF medication and treatment. This can be one of the most difficult aspects of becoming independent for both you and your parents who have been so involved with your clinic appointments.

Here are a few important tips:

- Don't guess when it comes to taking your medication.
- Make sure when you leave the Respiratory Clinic that you know exactly what medication you need, how much, what it is or and how long it will take before you see results.
- If you don't understand the instructions or how to use the equipment or medication, call the clinic to find out. It is completely normal not to take everything in during an appointment. Not everyone understands the details about their medication so easily.
- Don't feel embarrassed to ask questions and learn exactly what it is you have to do.
- Take notes during a clinic appointment or ask a family member or friend to be a second set of ears for you.

Tips for how to stand up for yourself with other people

There will be times when the people you interact with as a young adult such as doctors, nurses, employers, parents, friends, or organisations like Centrelink ,aren't always doing what sits comfortably with you. Below are some suggestions for the best ways to stand up for yourself and get your point across with the least amount of pain:

- Be positive and clear about what you want. Be honest, plan/list what issues are the most important to you. Select your most winning points to begin with.
- Gather facts, figures or documents needed and have your documentation sorted so it is easy to find if needed.
- Know the policies or guidelines, or find someone to explain them to you.
- Know what options are involved to solve the situation.
- If necessary, have an ideal outcome and a compromised outcome. Be prepared to compromise.
- Avoid entering a meeting or discussion angry. Try to let off steam beforehand.
- If you are negotiating on the phone, always make sure you know the name and position of the person you are speaking to so you can follow up with them next time, if needed.
- Be yourself.
- Listen carefully.
- Don't get into personal attacks on individuals. Stick to the relevant facts and issues.
- Ask for important issues or decisions to be formally noted in writing.
- Don't accept "cop- out" excuses for indecision or lack of action (politely).
- Be prepared to follow- up to ensure that the things which are agreed to are done.

Making a complaint about a health service

If you wish to make a complaint about a health service, you have the right to do so via the Office of Health Review, which is an independent statutory body set up to deal with disability and health complaints. Please consult the brochure provided in your Transition Pack for further information.

Office of Health Review

web: www.healthreview.wa.gov.au

phone: 08 9323 0600

email: mail@healthreview.wa.gov.au

4. Tips for Smooth Living With Your Parents

It is much more difficult to live out of home these days, mainly due to the rising costs of accommodation and everything else! Many young people have little choice but to remain living with their parents until they can afford to move out.

You may be very fortunate and have a fantastic relationship with your parents, so much so that living at home with them is great. Other young people, however, experience the following thoughts from time to time:

- Why don't my parents listen to what I have to say?
- Why are they so protective?
- What do my parents really think?
- Why do they think they know everything?
- Why do they say "Because I said so?"
- Why don't they believe what I say?
- For me to understand them, I would like them to understand me.
- Why are they so grumpy all of the time?
- Why can't they understand that things are different now for young people?

Here are some tips for encouraging a great relationship with your parents while you live in their house:

Renegotiate house rules/chores

- Discuss with your parents what their expectations are for the chores they would like you to do, having late nights out, friends over and pets. Work out a timetable that is fair to your parents and also to yourself (and any siblings).
- How much money you should contribute (especially if you are working). If you show respect and consideration for their point of view, they will be less likely to nag you. If you don't earn an income, think of some helpful ways to be of assistance such as cooking from time- to -time or help with the cleaning.
- Many of your parents' rules will be about ensuring your safety so communicating with them about your whereabouts reduces their stress and worry.
- Try your best to act like an adult when you and your parents disagree. This is very difficult but yelling and getting angry is only going to make them see you as an immature kid throwing a tantrum- so you will be less likely to be treated with the respect that you want. If you are feeling very angry, take a deep breath, remove yourself from the room, calm yourself down and speak to your parents when you are clear headed.

Your social life

- What do your parents think about you having friends or girlfriends/boyfriends to stay over? Negotiate with them what is a reasonable situation. While your parents might know that you are sexually active, they might not be comfortable with it in their home.
- If they are against you having a boyfriend/girlfriend stay over you will need to accept this and show your parents that you are reliable and mature by sticking to their expectations. They may change their mind later on.

Don't Wear Out Your Welcome

- Have a deadline for when you want to move out, even if this is a few years in the future. This will show your parents that you have serious plans to move on to the next stage of your life. It may take you a few years to save and accumulate the furniture, but having a goal and sticking to it will help you move towards independence. Your goal should be to get your parents to see you as a responsible adult.

Here are some more tips for living under one roof with your parents:

- Occasionally try to listen to your parents when they speak to you – they like it, and it keeps them quiet for a while.
- Occasionally doing something small and helpful without being asked makes your life a lot easier – it's a mental thing; they think you're being helpful so won't ask you to do anything else that will certainly be bigger and more cumbersome. Attack is definitely the best form of defence on this one!
- Apart from the TV, feign total ignorance on all technical matters; you know absolutely nothing about iPods/computers/radios. Failure to do so will result in you becoming in-house technical support. This is draining, annoying and means you get endless calls at weird times asking where the volume switch is on the DVD player (I know, extraordinary, but true). Instead, suggest they get a professional in to help them. Being charged by the hour concentrates their minds beautifully.
- Little things go a long way – buying the food just occasionally will make them think they have produced an angel. Actually cook it for them and you never need to lift another finger in your life.
- When tired and grumpy, retreat. I personally love a bit of confrontation when I'm grumpy. However, it is advisable not to use your live-in parents as your steam valve. They don't appreciate it and then you get the "I'm just very disappointed in you" chat – and who wants that?
- Lastly, the most important rule. Don't put the intimate birthday party you're giving while your parents are away on Facebook and then be surprised when the world turns up and trashes the place. There's a reason Facebook has privacy settings. Use them.

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5. Living Out of Home

You may be reaching the time when you want to move out from home, to have privacy, your own place, to entertain your friends, to not worry about waking parents up and to have more freedom. While there are many benefits to living with your parents, the steps towards becoming an independent adult can certainly be taken when you live out of home. It is also fairly common for young people to move out and then back in to their parents' house over the course of their early twenties and thirties (and sometimes even their forties and fifties!) depending on their financial situation.

Here are some hints and tips to consider while you plan your move:

Cost

- Do you know how much it will cost to live on your own or with flatmates? Have you worked out an estimated weekly or fortnightly budget, including rent, electricity, phone, internet connection, gas, water, petrol or transport fees, groceries, clothes, medication costs, dental, fun.
- If possible, it is really worth planning ahead and saving for the move. The cost of moving and setting up a house can be very expensive. Your parents may not be in a financial position to assist you, and you may find yourself stuck.
- Will you be able to afford to have a savings account too, to cover unexpected things such as your car breaking down? If you have a decent amount of savings to cover a couple of months' worth of living expenses then you are in a really good position to cover job loss and so on without having to move back home.
- How will you move your furniture to the house? Will you need a removalist or can you hire a vehicle? Do you have friends with utes to help? Factor the cost into your overall moving costs.

Food

- Do you know how to cook? If not, maybe it's time to find out how your mum or dad make your favourite recipes or buy a basic cookbook. You can also look online for the things that you like that fit in with your food budget.
- Sometimes you find the types of foods your parents can afford, you may not be able to, when living out of home. What takeaway establishments are close by to where you plan to live? (VERY IMPORTANT!)

Cleaning

- What are your basic housekeeping skills like? If you are moving out with friends, what are they like? Basic hygiene in a house is really important for your overall health. If things aren't cleaned on a regular basis, there is more risk of food poisoning, catching colds, scabies etc.
- Housekeeping is quite time- consuming, so how will you fit it in with your work or studies, doing your CF treatment, going to hospital if need be and socialising?
- Sometimes before flatmates live together they negotiate who is going to do what. Some people like to do the shopping and cooking, while others prefer to mop and vacuum. If everyone is on the same page and helps out this makes for a happy time living together.

Your parents

What is your relationship with your parents like? If it is not so good think about trying to make up with them, as you will still need their support on occasions once you have moved out. Your parents may also be very sad that you have moved out so they may not seem themselves at first. But once they see that you are happy, safe and healthy they will be more supportive and accept your move.

Your new place

- Make sure your flat is warm, clean and dry. Avoid mould! Let flatmates know about your health needs, keep wet clothes out of the house and insist that there is no smoking around you.
- What items will you need if you are moving into an unfurnished place? What items will your flatmates contribute? Often family and friends can be a great help providing you with household items that they no longer need. Garage sales or swap meets are also great places to look for household items to start you off, or IKEA!

- Make a list of all the essential items and then once you have moved in and can save a bit, think about the fun novelty items that stamp your personality on your place. If you consult your parents about the types of things you need to set up a place, it allows them to share in your planning and gives you the benefit of their wisdom and experience.
- When you first move into a place,(and if you are sharing/have flatmates), don't purchase really good, expensive items to start with until you know what it is like living with these people, as sometimes your good things can end up being ruined.

When looking at a place, check:

- If it has air-conditioning.
- Is it well ventilated (no mould in bathrooms etc)?
- Have pets lived their before? Do you have, or are you planning on having pets?
- Is there decent public transport accessible if your car breaks down?
- Are you close to your work?
- Are you close to your parents or other friends and family if you need their support?
- Is there a good space for you to fit friends, family etc. when they come to visit?
- Are there shops close by? Where is the nearest bank or Centrelink etc?

Your Flatmates

- Smoking: Are your friends smokers or do they have close friends who will be visiting often who smoke? What is the policy going to be? Smoking outside and where? Who will clean the ashtrays? Living with smokers who smoke inside can result in all your clothes, furniture and items being exposed to extreme amounts of cigarette smoke, which is very bad for CF!
- Living with your friends can be lots of fun and bring you closer together. You can have some of the best times of your life but it can also make you very annoyed and sometimes break friendships if your flatmates have different ways of doing things that affect your life e.g. not doing their share of the housework, eating your food, breaking your things etc. Make sure you discuss in detail any possible differences that you may have and make it clear who is going to do what.

Legal obligations of tenants

- Whether you are renting a place through a real estate agent or privately, there are legal obligations tied to this. There will be lease documents to sign. It is a good idea to have your parents or an older adult look over the contract before you sign to make sure everything is in order. Usually when you rent accommodation you need 4 weeks' rent to pay upfront plus 4 weeks' rent which becomes the bond. You do not get the bond back until you move out and if the owner or real estate agent accepts that the accommodation is in good order.
- It is in your and your flatmates best interest to be good tenants, especially if you are renting through a real estate agency. They keep your rental history on file for a short period of time, so if you need to find another place it can be difficult if you have a bad rental history.
- INSPECTION TIME… always make sure your home is spotless for every inspection, especially the first one! After the first inspection you will be able to tell what the real-estate agent will expect from you and if you get a letter stating that certain things were not up to scratch, fix those things ASAP. You don't want to get on the bad side of your real-estate agent (they can may life very difficult if you want to find another place to rent later on!).

6. Working and CF

In order to fully join the world of adulthood and take charge of your life, employment is important, whether it is part- time, full- time or casual. When considering what career path you wish to pursue, focus on what you physically and mentally are able to do, as opposed to what you can't do. Persistence is the key to gaining either your dream job or a temporary position. Don't give up and allow setbacks to prevent you from achieving your goals, you will get there as long as you keep at it. There's a great job out there for you!

Another very important point is that once you do gain employment, make it a priority to also look after your health. If your employer sees that you are willing to do the best for yourself, you can rightfully expect them to make some allowances for your health needs.

Having CF can cause limitations on certain types of employment that you may really wish to do e.g. deep sea diving. But there are also a great deal of things you can do! With a bit of planning and forward thinking you can achieve your goals even if there are bumps along the way.

Remember also that The Disability Discrimination Act makes it unlawful for employers to discriminate against people with disabilities (e.g. illness) in employment, including recruitment, terms and conditions of employment, and dismissal or termination. Refer to http://ww.hreoc.gov.au/disability_rights/legislation/index.htm for further details.

Plan for what you want to do

- Dream about the future and think about practical ways to make those dreams a reality.
- Plan, and take positive steps to carry out your plans.
- Be on the lookout for unexpected career opportunities and be willing to pursue them.
- Make a list of all the people you know (your network of contacts) who may be able to offer you a job such as friends' parents, next- door neighbours or a contact on Face Book.
- Ask to do a short amount of work experience or visit different workplaces to see how they operate.
- Identify role models you admire and find a mentor such as someone within your network of family or friends, or even people in the CF community. (CFWA can help you link up with different members)
- Talk to your parents or caregivers about your future, listen to their advice (as parents have a wealth of experience), but also listen to what your dreams and goals are.

Things to consider when seeking employment

- Will you be exposed to pathogens, chemicals and bugs? (Jobs in agriculture, working with animals or in laboratory situations might carry extra risk.) If so, what protective equipment does the company provide? How much exposure will you have?
- Will the job be physically demanding? How will you handle this if you are less well? If you wish to choose a trade that is physically demanding, look for a company that has the option of changing to a less physically demanding job in the future –usually in larger firms.
- Energy levels: are you able to push yourself or do you tire easily and need to limit activities?
- Consider whether you want to work full-time or part-time.
- Brainstorm your skills and relate these to key aspects of the job you are applying for.

  Family and friends can also identify your strengths so it may be a good idea to ask for their input when you are writing a job application.
- What are your requirements for scheduled time off for hospital admissions? Some people with CF who work negotiate with the CF clinic when they will have admissions for regular "tune-ups".
- What are your coping abilities? Do you cope easily with life and with the challenges of managing CF or do day-to-day stresses get you down?

- Maybe it might help to think of yourself as a brand (like Kylie Minogue or David Beckham). What "package" of skills and experiences can you offer? What are your strengths and interests? Even if you haven't worked before, you may do things at home e.g. organise younger brothers and sisters to get ready for school, helping with sausage sizzles at the football club, organising parties etc. These experiences all contribute to giving you skills that can be useful in paid employment.
- Employment conditions: are there flexible work arrangements? Sick leave allowance - unpaid days off if needed?
- What is the work environment like? Do they have a place where you can do your treatment if need be? Will you need a fridge to store any medication?
- Does the company have a health insurance policy plan, if you need to stay in hospital or have a lung transplant, which would cover long absences? It is good to think long term.
- What is the company policy on disability/illness and how widely is this circulated?
- Does the company actively promote employment opportunities for people with illnesses?

You can ask all these questions of a few companies before you apply for a job, so you get a feel for what different companies offer. Or some information may be found on the company's website.

Self employment

Many people with CF prefer to run their own business as this alternative can allow for more flexibility in work hours and the option to work from home.

The disadvantages of working for yourself are that if you are unwell, there is no sick leave or possibly anyone to cover the work that needs doing, which means no income for the times when you are sick. It is also common for self- employed people to work longer hours than those who work for an employer. However, some people have a small business they run from home e.g. a web- based business, which needs little maintenance while also working for a company or organisation part-time.

Tips for job interviews

Job interviews can be very daunting, especially when you are being judged on everything from what you are wearing to what you say. Just remember that the employer is seeking the best person for the job and who will also "fit" in with their work environment. Sometimes you can have all the right qualifications and experience and not gain the job due to the fact that someone else (may have) seemed like a better fit with the organisation.

You can't control who you are competing with in job interviews or what type of person the employer is looking for, but you can control how you look and act. If you experience knockbacks, try your best not to take it personally (although that is very difficult because it can feel like a major rejection!). The more jobs you apply for, the more interviews you attend, the more chance you have of finding a fantastic job that you really enjoy. Often if you did not gain a position with the company, it can be a blessing in disguise because there will be something better around the corner which will be perfect for you.

- Dress the part: Even if the job you're applying for involves wearing a uniform or working behind the scenes, the way you dress for an interview tells your potential employer that you take the job seriously. For men, wear a nice pair of pants with a shirt and a tie if you are applying for a job in an office environment. Sneakers, sandals, shorts, T-shirts, sweatshirts, and jeans don't make good interview attire. The same goes for women — wear something simple and avoid short skirts or skimpy tops. Make sure your hair is neat and clothing is clean. Check your nails are neat and tidy too!
- Appear confident: Even if you are really nervous try your best to control your mannerisms and body language. Potential employers understand that it is nerve-wracking going for an interview and they really just want to find out about you and your experiences to see if you match up to the job. If you allow your nerves to rule, you won't be able to sell yourself as well. Take deep breaths, have some water with you and make sure you look your potential employer in the eye, shake his or her hand, and speak clearly and politely. If you are interviewed by a panel of people, make sure you look all of them in the eye and address each of them, when appropriate.
- Be yourself: Even though you may be nervous it is best to be genuine and honest in interviews. Employers can usually tell if a person is not being honest. There is nothing wrong with extending things a bit or making things sound more than they really are (this is marketing!) but if you really don't know the answer to a question or haven't got a particular skill they are seeking it is best to be honest.
- Be prepared: Find out what you can about the position, or company, in advance and show your knowledge during the interview. You would be surprised how many people don't do this and it really can make you look impressive if you have done your research. Researching the company shows the interviewer that you're smart and eager to learn. Doing your research also lets you learn what inspires you about the company so you can share your enthusiasm with the interviewer.
- If you can find out more about the position itself: Looking on the company's website or talking to someone who has worked there allows you to think in advance about which skills you have that fit well with the job. Don't be afraid to ring beforehand to ask if you can speak to someone about the position. This shows that you are enthusiastic.

Answering the interview questions

Interviews can involve a quick five minute chat or a couple of hours where you have to also fill in paperwork, answer questions and complete skill tests e.g. typing or computer tests. Sometimes employers will interview people in a group situation.

No matter what the style of interview you may be asked the following types of questions:

- Why are you interested in the position?
- What type of skills can you offer the organisation?
- How do you handle difficult or stressful situations?
- What are your weaknesses and strengths?
- How do you organise your time/workload?
- Do you work well with a team and also on your own?
- What hours are you available to work?
- Give examples of your previous work experience.

Ask your parents, other family members or friends what sort of questions they were asked in job interviews and ask them what they think are good answers. Think about and prepare the types of answers you want to give before the interview and relate your experiences to the particular job requirements.

Ask questions

During the interview don't be afraid to ask questions. Questions don't make you look stupid. Asking good questions shows the interviewer you're thoughtful and that you're not afraid to interact with other people — a particularly good interview strategy if the position involves dealing with people, such as sales.

Some questions to ask about the organisation could be:

- What is the organisation's plans for the future?
- How many people work there? What is the staff turnover like?
- How long has the company been established for?
- Is there a non-smoking policy?
- Is the position for long or short-term?

Parents or older siblings can offer good advice about job hunting and interviewing, so don't hesitate to ask for help on everything from putting together your resumé to choosing an interview outfit.

Whether or not to disclose that you have CF at interview stage

- It is an individual choice to disclose that you have CF during an interview. If you are asked whether you have a health problem or disability, it is best to answer in a straightforward way. If you don't mention that you have CF, you may lose some legal rights relating to unfair dismissal if that were to happen down the track.
- Disclosing that you have CF at the interview can put you and the company in a difficult position. If you feel you can do the job as it is presented to you, having CF should have no bearing on the job.

  The decision to hire you should be based on your ability to perform the physical and mental tasks of the job. If you need to provide references, make sure your referees do not mention that you have CF if you do not wish to disclose this at the initial stage.
- Once offered the position, legally you do not have to mention that you have CF, however if you plan to stay at the job for a longer period of time, you will need to disclose this at some stage in case you need time off for hospital appointments or admissions.
- When you start a new job, talk to your employer or line manager in more depth about how CF may affect your work.

Once you have gained employment

Once you have settled in to your new job it might be a good idea to establish a contingency plan about how any future absences will be managed. Is it possible for you to "bank" your time to allow for any absences?

Planning ahead allows you to give your employer notice as to when you need time off so that they can also make plans for adequate cover while you are away. In some cases, if you need to be admitted to hospital, you may be able to make arrangements to continue working via a laptop, or even go to work during the day and return to the hospital at night.

Keeping your job

Before reducing the hours that you work due to health reasons, consider whether adjustments could be made to working arrangements instead: would a different job within the organisation make life easier?

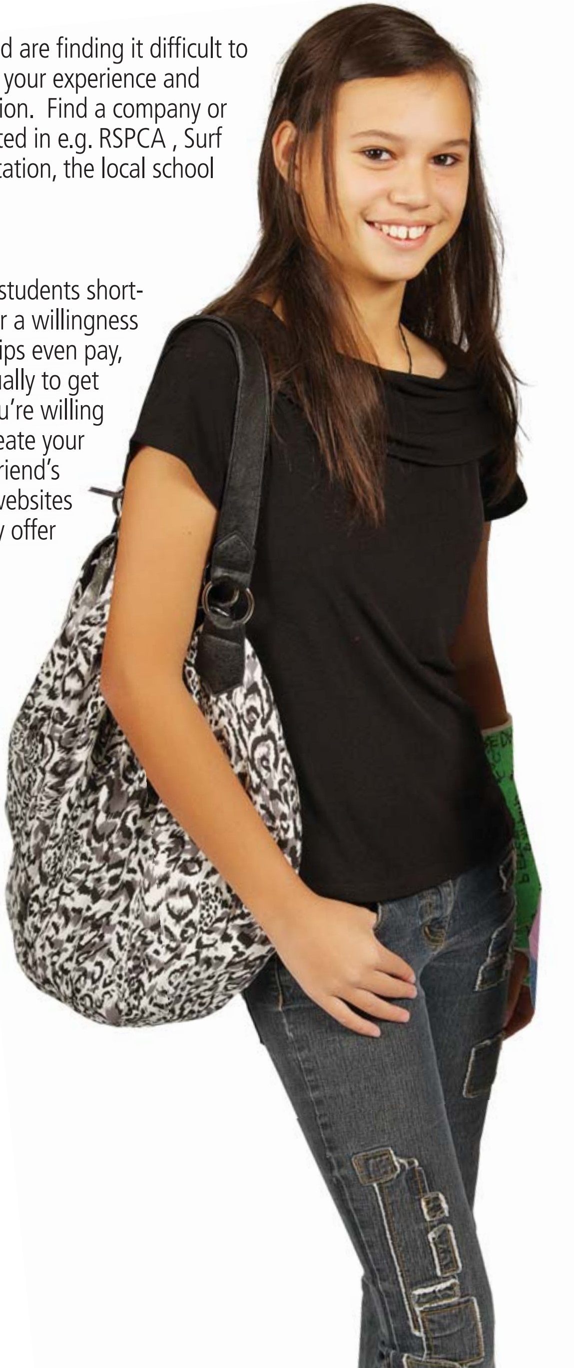
Could you establish a contingency plan about how any absences will be managed?

Volunteering

If you have just finished high school and are finding it difficult to gain employment, a great way to build your experience and resumé is to volunteer for an organisation. Find a company or organisation that you are really interested in e.g. RSPCA , Surf Club, Salvation Army, university radio station, the local school or a retail outlet.

Internships

Some companies and businesses offer students short-term, hands-on training in exchange for a willingness to learn and work hard. A few internships even pay, although the point of internships is usually to get work experience, not earn money. If you're willing to work for free, you may be able to create your own position at a family member's or friend's company. Alternatively, check out the websites of companies in your area to see if they offer internships.



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7. Further Study and CF

As there is such a wide variation between people with CF, you may not consider yourself to have a disability, however, if you find that you need hospitalisation or your illness impacts on your ability to study, it is worth considering how your chosen university or college will cater for your needs.

It is also worth considering that your chosen course may take three or more years to complete. You will need to think long- term about your health and how it may impact on your studies. Consider if the qualification will lead you to a job where you are likely to have a supportive employer during times of illness?

All Higher Education Institutions are required to submit a disability statement. Universities and TAFE must ensure that students with a disability receive non-discriminatory treatment. This is a requirement of the Disability Discrimination Act (1992). For information about the Disability Discrimination Act see the Human Rights and Equal Opportunity Commission Website at http://ww.hreoc.gov.au/disability_rights/legislation/index.htm

Choosing the Right Course and Subjects

In order to ensure you match your interests and skills to the right course, it can be well worth the effort and time to speak to people who are currently employed in your area of interest. How flexible will the actual career be if you need to take time off for hospital admissions? Can the job be done full -time or part-time?

It is also well worth attending Open Days, speaking to career advisers, finding out about prerequisites for particular courses and whether the course requires you to go on practical work experience. (How will that impact on you if you also have to work?)

You may also need to consider things like parking, access to public transport and accommodation offered by the university or TAFE.

Studying Full-time or Part-time

Consider whether studying part time or full time will suit you. Although it takes longer to complete a course when studying part- time, you have more flexibility to take care of your health, work and adjust to life after high school. You may decide to alter whether you study full-time or part-time as you go. How flexible is your chosen course in allowing such adjustments?

Special Entry/Equity Schemes

Some universities and TAFEs offer special entry or equity schemes which can provide further opportunity for students to access study. They take into consideration factors such as illness, financial hardship or other issues that may impact on a person's ability to compete with other applicants.

Disclosure: To tell or not to tell?

Students may choose to disclose to an education institution prior to enrolment that they have an illness to:

- Find out information about available support and services.
- Find out how to access services once they are enrolled.
- Discuss course requirements to ensure that the appropriate course is chosen.
- Assist in the transition from secondary study to TAFE or university study.

Reasons not to disclose your medical condition:

- You may not require any additional support or services.
- You may wish to wait until you are certain about which institution you are attending.
- You may be uncertain about who will have access to your personal information.

It is not always essential to disclose specific medical or personal information about a disability prior to enrolment. What is most important and helpful is to provide information about how your disability impacts on your capacity to study and what support is needed to assist in providing the optimum environment for study to occur.

Once you have gained a place

Plan a course of study that is not crammed full of classes, labs and tutorials all day, every day. Plan for time to rest and to look after your health. Better to choose fewer classes and get great marks than more classes with mediocre results (and your health also doesn't suffer).

It may be useful to discuss your individual experiences as a person with CF with a course lecturer or a disabilities service officer.

Points to discuss and consider:

- You may need to discuss the course requirements and negotiate how you will cope with the workload.
- You may need to point out that your quality of work could fluctuate according to your health.
- There may be times in the term when you are unable to work effectively and attendance at lectures may be erratic.
- It is also helpful to discuss how you personally react to feeling tired or ill.
- You will need to work out a plan of how you will be able to get information that you have missed e.g. organise a study buddy who can send you any information, handouts etc.
- What are the procedures with exams if you are unable to attend?
- Do you require special considerations e.g. rest breaks, a separate room to sit?
- You will also need to find out if there is flexibility to alter the work schedule, deadlines for work and deadlines for return of library books?

Taking control of your studies

Some of the suggestions that the Career Tips website offers in relation to taking control of your studies are:

- Be flexible about the options that may provide you with appropriate individualised support, i.e. treat your own and everyone else's suggestions as a possible option. The more options you have to choose from, the more likely you will find the best choice.
- Be persistent and committed.
- Celebrate your successes with lecturers, classmates, friends and family.

According to the Career Development Centre other things to consider when studying are:

- Identify your support network e.g. family, friends, doctors, lecturers.
- Manage stress by setting priorities such as eating well, doing regular exercise and getting enough rest (your health should come first!)
- Give yourself time to adjust to the changes that await you once you finish high school.
- Remember, it is YOUR decision – be confident in your ability to choose what is right for you.

Also consider that it is useful to review how you are going halfway through each term and speak to the Disabilities Officer or course coordinator if you find you need to reassess how you are coping.

The Career Development Centre can assist with career planning, educational and other training options. Their website is www.det.wa.edu.au/training/cdc or career.development@det.wa.edu.au

Tel: 08 9224 6500 or 1800 999 167 (for country callers)

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8. Travel and CF

Now that you are a young adult you may want to go and explore the world with friends, family or by yourself! Having CF shouldn't stop you from travelling, however, there are some specific things that you do need to consider before you leave for your adventure.

Informing the CF team

It is important to inform the CF team at SCGH before booking a flight. You may need a formal flight test to assess if in-flight oxygen is required. This is to avoid potential hypoxemia (low oxygen) when flying at a high altitude.

Insurance

Travel Insurance is not a fun aspect of travelling but it is essential to research and find a good insurer. It covers everything from broken bones to lost luggage, but unless you're approved for 'pre-existing condition' cover, it won't pay for CF-related medical expenses. If you are in good health you may think you don't need it, but if you have any accidents or need any CF-related treatments, you may be largely out- of- pocket if you are not covered.

The following are some important points for applying for travel insurance:

- Apply within 90 days before you plan to leave. Do not leave it until the last minute.
- Apply to a number of travel insurance companies for pre-existing cover at the same time. If you only apply to one company and are rejected, you will have to disclose that fact when you complete the application form for the next company.
- It is essential to obtain a letter from your CF specialist providing details of your state of health, a list of your current medications and your treatment plan. Some information about your medical history e.g. frequency of hospitalisations could also be useful.
- Ask your CF specialist (rather than your GP) to complete the medical report section of the application. They are more likely to know details of your hospitalisations, medications etc. If you are applying to multiple insurance companies, choose the most comprehensive medical form and ask your specialist to complete it. You can then photocopy that completed report to submit to all the insurance companies – it will save your specialist completing multiple forms.
- Provide an outline of your travel plans and itinerary.
- It may not be possible to obtain cover for long-term travel. Bear in mind that you will be able to obtain ordinary travel insurance which covers you for most things e.g. losing your luggage, breaking your leg, etc. The only problem can be getting cover for CF (pre-existing condition). If you haven’t declared it and need to be hospitalised for CF when you’re away, you will not be covered.
- Most travel insurance policies provide all medical and non-medical insurance cover for people with chronic illnesses except for claims relating to pre-existing medical conditions.
- Most insurance policies define pre-existing medical conditions as a medical condition which pre-dates the commencement of the insurance policy and with respect to which the person had received advice, treatment and/or medication within 30 days, 60 days, 90 days or maybe 180 days before the commencement of the policy.
- There are some policies where some prescribed pre-existing medical conditions are fully covered, e.g. some asthma, epilepsy, non-insulin-dependent diabetes, strokes more than 12 months ago and some cancers. Some policies will include cover for pre-existing conditions if you fill in a health questionnaire and it is accepted.
- It is always a good idea to check the above before actually applying for insurance cover because any refusal of insurance cover will count against you if you apply for insurance cover with a different insurer.

What to pack

You may find your medication takes up a lot of room and it is tempting to cut down on some things, but it is better to prepare for anything! Plane travel, a busy itinerary, exposure to a different climate and pollution could all have an impact on your health.

A good idea is to carry a small supply of your most essential medication in your carry-on luggage in case any luggage goes missing.

The power supply can be different in other countries so you may need an adapter for your nebuliser and, of course, your hairdryer!

Documents and letters

Carry a letter from your doctor at SCGH explaining your condition and listing all the medications and equipment you'll be carrying, including syringes for nebuliser preparation, insulin needles, and any OTC drugs such as Panadeine. This is as important as your passport. It will help if you need to see a doctor, but it's vital if you're questioned at customs. Get the brand names right.

Physio

It's tricky trying to keep up your physiotherapy regime when you're on holiday, especially if you're on a bus, train or plane for long hours or if you're constantly on the move. Try enlisting a couple of your travelling companions to give you a reminder if they notice when you're getting slack.

Reciprocal health agreements with other countries

Australia has a reciprocal health agreement with the UK through the UK NHS. The Medicare Australia website has details about this and other countries . To find out more details visit
http://www.medicareaustralia.gov.au/public/migrants/travelling/index.jsp

Plan your travel carefully and remember that some countries, such as those in Asia and many developing countries, have no, or limited facilities for CF care.

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www.cysticfibrosis.org.au > About CF> Living with CF> Travel overseas

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9. When Things are Tough: Grief, Anxiety & Depression

Living with a health condition

It’s understandable that some people affected by a chronic illness such as CF can, by the time they are a young adult, feel fed up with having to deal with their illness. It’s also very easy for a health condition to become the main focus of someone’s life — especially as that person first learns about and starts dealing with the condition. Many people find that reminding themselves that their condition is only one part of who they are can help put things back in perspective.

It is completely understandable that having lived with CF since childhood, wanting to live a “normal life” would be most desirable without the limitations of having to do physiotherapy and take medication every day. It may seem very tempting if you are feeling healthy and strong (or even if you aren’t) to skip some of your treatments. Unfortunately, in the long run, if you neglect your particular treatment regime, it can have disastrous results. If you are really struggling with balancing your life and your treatment (which is completely normal!) speak to the team at SCGH to find out some solutions and discuss the things you really want to be able to do but can’t at the moment. This is all part of taking more control and becoming a player in your own medical care.

Adjusting to living with a chronic illness takes time, patience, support and willingness to learn and participate. People who deal with unexpected challenges often find an inner resilience they might not have known was there before. Many say that they learn more about themselves through dealing with these challenges and feel they grow to be stronger and more self-aware than they would be if they’d never faced their particular challenge. People living with chronic illnesses find that when they take an active role in taking care of their body, they grow to understand and appreciate their strengths and adapt to their weaknesses as never before.

Understanding other people’s reactions

You may not be the only one who feels emotional about your illness. Parents often struggle with seeing their children sick because they want to prevent anything bad from happening to their kids. Some parents feel guilty or think they’ve failed their child, while others may get mad about how unfair it seems. Everyone else’s emotions can seem like an extra burden on people who are sick when of course it’s not their fault. Sometimes it helps to explain to a parent that when you express anger or fear, you’re simply asking for their support — not for them to cure you. Tell your parents you don’t expect them to have all the answers but it helps if they just listen to how you feel and let you know they understand.

Grief

Living with CF is certainly tricky but on top of that, there are times when you may experience, or have already experienced, some other really tough things like a death of a loved one, parents getting divorced, unemployment, domestic violence, getting into trouble with the police, moving away from your close friends, breaking up with a girlfriend or boyfriend, the list is endless.

Difficult or painful situations can cause anxiety or even grief. Grief is a normal human response and everyone grieves differently. There is no right or wrong way to recover from a traumatic experience, and there are no secret methods or rules. Some people underestimate how long it will take them to get through a difficult time, but however long it takes, grief does get easier to handle.

Grief is not just an emotion; it also affects people physically, socially and spiritually.

But whatever the situation, you can get through it - even if it sometimes feels like you never will.

Gradually we start to feel more okay than we did before. The intensity of what we're feeling and experiencing will decrease. "Feeling okay again" usually happens slowly, often without us even being aware of it. We start to realise things aren't quite as rough for us as they were before.

It can be very useful to talk to someone about how you are feeling. A close friend or family member, a counsellor, doctor or a helpline, can all be very good supports. The most important factor when seeking help isn't necessarily finding someone who knows a lot about your illness, but finding someone who is willing to listen when you're depressed, angry, frustrated — or even just unhappy. Noticing the emotions you have, accepting them as a natural part of what you're going through, and expressing or sharing your emotions in a way that feels comfortable can help you feel better about things.

Anxiety

Feeling anxious about various things such as a job interview, going out with someone new, or getting a medical checkup or intervention is a normal part of life. Normal anxious feelings last for a couple of days and can help you perform at your best. However, if someone feels so anxious that it affects other parts of their life such as how they interact with friends or family, and the feeling lasts for weeks, months or even longer, then it can mean the person is experiencing an anxiety disorder.

In Australia, one in ten people between the ages of 18 and 25 experience an anxiety disorder within a twelve month period.

Anxiety is quite treatable. If you are experiencing anxiety to such an extent that it is affecting your day-to-day life, then seeking help to recover is a great idea. Sometimes people who are stressed or anxious feel very trapped and can't think of a way out of the situation that is bothering them – if this is the case, it can be very helpful to find someone you trust to talk to. Intense and ongoing anxiety can lead to depression.

Seeking assistance can enable you to see your situation from another perspective, help you make a plan of what you need to do – and what things can wait. Speaking to someone can also help you to work out what you might do differently.

Depression

It is not uncommon for people to feel down or depressed from time to time. Sometimes having an argument with a friend, being unemployed or fighting with your parents can make you feel depressed. Sometimes you can feel 'down' for no reason at all.

Depression can become an illness when the mood state is severe, it lasts for two or more weeks and it interferes with a person's ability to function at home or at work.

Signs of a depressed mood include:

- Lowered self-esteem (or self-worth)
- Change in sleep patterns, that is, insomnia or broken sleep
- Changes in appetite or weight
- Less ability to control emotions such as pessimism, anger, guilt, irritability and anxiety
- Varying emotions throughout the day, for example, feeling worse in the morning and better as the day progresses
- Reduced capacity to experience pleasure: you can't enjoy what's happening now, nor look forward to anything with pleasure. Hobbies and interests drop off.
- Reduced pain tolerance: you are less able to tolerate aches and pains and may have a host of new ailments
- Changed sex drive: absent or reduced
- Poor concentration and memory
- Reduced motivation: it doesn't seem worth the effort to do anything, things seem meaningless
- Lowered energy levels.

Having one of these signs/symptoms by itself, is unlikely to indicate depression, however, there could be other causes which may warrant medical assessment.

If you have several of these feelings and they persist for most of every day for two weeks or longer, and interfere with your ability to cope at home and at work, then seeing a GP is a good start for help and information. Your GP can help you work out if what you are feeling is depression and assist with planning how to get through it.

For some people, the doctor may think that antidepressant medication is also necessary, but only if the depression is severe or it isn't improving with other treatments. If you do start taking an antidepressant, your doctor will monitor you closely for a while. If you are feeling suicidal it is very important to seek immediate help.

Whatever your treatment, there are many things you can do to help yourself recover.

- Try to stay physically active.
- Plan what you are going to do each day, even small things like going to the movies or talking to a friend.
- Get plenty of sleep.
- Try not to drink or take drugs – 'blocking out' how you're feeling usually only makes the problem worse.

It's not easy to say exactly what causes depression – it's different for each person. Sometimes a difficult time in a person's life can set off depression and sometimes it's caused by combinations of things that build up over time. Sometimes, there is no obvious cause at all. Some causes of depression could be due to genetics, biochemical, illness, gender, stress and personality.

Depression is just like any other illness – you need ways to get through it and stop it happening again later on. Some people think that it's weak to admit that they're going through a tough time. But if you have depression, you can't just 'snap out of it' or 'pull yourself together'. Keeping it to yourself only makes things worse. Start by talking to someone you trust – maybe a parent, family member or friend.

For further information and support

You can also speak to trained counselors by phoning;

- Lifeline – 13 11 14 is a 24-hour telephone counseling service (cost of a local call)

Information and support is also available from these websites

- Beyondblue – www.beyondblue.org.au or www.youthbeyondblue.com, info line 1300 22 4636 (cost of a local call from a landline)
- Headspace – www.headspace.org.au
- Reachout – www.reachout.com

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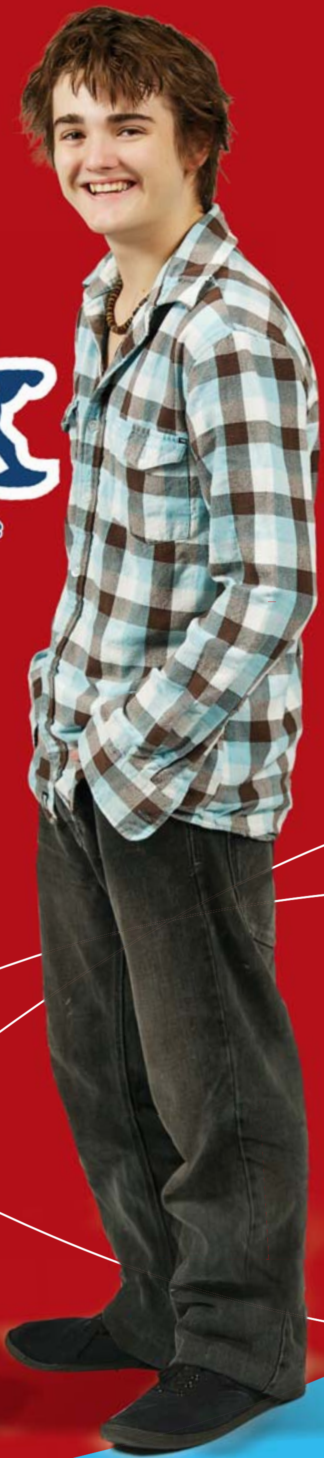
Note:

transition pack

moving to adult care



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