

TIPS AND IDEAS FOR HIGH SCHOOL STUDENTS WITH CF



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Many thanks to Janette Hayward, an adult with CF who wrote the original version of this booklet.

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1. High school and CF

High school has its challenges for everyone and it can be harder for people with CF. Looking after yourself can take more time and effort than for people who don't have a long term health condition.

From time to time you may have less energy than your friends and less energy means that keeping up with school work, sports and having fun can be tricky.

There will be other students at your high school with a variety of health conditions so you won't be the only person having to balance daily treatment with school work but sometimes it might feel like you are the only one.

Just as CF affects you differently from other people who have CF, so will your experience of high school be different from others. The sections in this booklet have been developed to provide hints and tips for navigating your way through high school. Of course not all parts will be relevant to you – but we hope there will be something for everyone amongst the many tips and ideas.

2. Telling your teachers about your CF

You're in charge of what information is known and shared about you and therefore it's up to you whether you let your teachers know about your CF and how it affects you. However, with more understanding about CF and your needs, teachers are in a much better position to help you and support you in the most effective way they can. If they understand the challenges you face – then they can plan and work with you so you can have the best possible school experience.

You know so much about CF as you live with it every day – but many teachers will know little or nothing about it or what they know might be out of date with the information they do know.

If you are happy to tell your teachers, think about when to do this. Do you want to update everyone at the beginning of each school year when you know who your teachers are? Would you like to talk to all of your teachers as a group or talk to each one individually? Would you prefer to talk with your year co-ordinator one-on-one and then they can pass the information onto all of your teachers? Perhaps you would like your parents to be involved or to take care of the whole thing on your behalf? Maybe you think it's best to only talk about your CF if you need to when you are feeling unwell or need extra treatment.

There is no right or wrong way to proceed and you can do what feels right for you each year. What's right for you in Year 7 might not be right for you in Year 12. As you move through the years in high school your approach to this will probably change.

Here are some ideas and resources that can help with whatever you choose to do - you may find it helpful to use a combination.

A. Video for teachers about having a student with CF in their class

Charly talks to her teacher about having CF and how it impacts on her time in school. This is a great introduction and overview for teachers. It can also give you some ideas if you want to talk to your teacher yourself. Charly talks about how she wants to do well at school and how the teacher can assist her to do this.

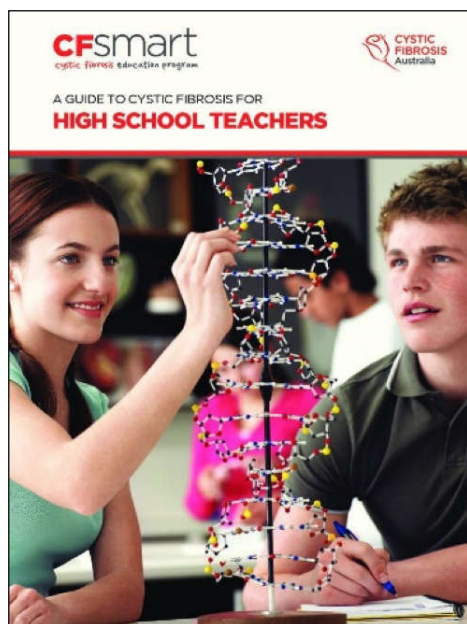


Helping Kids With Cystic Fibrosis Succeed in School - YouTube (6:49 mins)

<https://www.youtube.com/watch?v=EASUbdXnHrI>

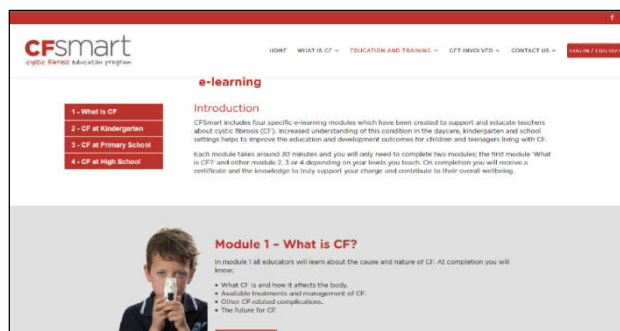
B. Free guide to Cystic Fibrosis for High School Teachers

There is a 14-page booklet on the CFSmart website **cfsmart.org** that has been written for High School teachers. If they don't already know about this, you can direct them to the website or download and send them a copy. Or your local CF organisation may be able to post a hard copy of the booklet to you or your school.



C. Free e-learning course for teachers all about CF

There is a free e-learning course that any of your High School teachers can take. It's made up of two modules of about 30 minutes each. The modules include a whole range of very informative videos and information about CF. Module 1 will give them an overview of what CF is and Module 4 is about CF and supporting students in a High School setting. This can be found on the CFSmart website **cfsmart.org**



D. Talk directly to your teacher(s)

Because CF affects everyone differently you want to make sure that your school and the teachers know how CF affects YOU as an individual and how they can help. It can therefore be very useful to sit down and let them know about any information that is specific to you.

The list below includes lots of different topics to get you thinking about which ones apply to you:

- What organs in your body are affected? Do you have CF Related Diabetes (CFRD) or osteoporosis? Are there other ways CF affects you like needing to go to the toilet at short notice?
- Letting your school/teachers know about the medications you take and treatments you do each day at home will give them an understanding of how much more you have to fit into every day compared to your friends.
- Will you need to take medication at school? Would you like to keep all of your medication with you to have as you need? Does any of the medication that you need at school require refrigeration? It makes sense for people with CF to keep their medication with them and you might need to explain why to your school or teachers. In some cases you might need back up so you may need to ask your CF clinic to write a letter to the school or ask your state CF organisation to speak to the school about it.

- Letting them know about clinic visits and potential hospital admissions will help your teachers understand why you are away from school more often and that they need to update you about what was taught and discussed in any lessons you miss. They will also understand that you have a legitimate reason for requesting extensions if you are unwell.
- Are you well enough to take part in regular PE? Does your PE teacher need to know you have CF and what activities you can or can't do? If you need Ventolin, Atrovent, salt tablets, extra water or you might need to take time out for a breather they will let you do so and not worry about you. If you do extra-curricular sport you might want to let your coach know too.
- It would be very useful for the school nurse (if your school has one) to know who you are, what CF is and how they can help you if you feel unwell during the day.
- Would it be helpful for you to have a locker in a centralised place in the school?
- Do you have times when you don't get much sleep due to coughing, so find it difficult getting to school in the mornings?
- Do you need/want special consideration and exam provisions? See the sections "Exams" and "Further study" for more info.

E. Write a letter or email

Another method is to write down all the information in a letter or email and send it to your teacher. This gives you time to think carefully about what you want your teachers to know. The other benefit is that the teachers can keep a copy of what you have written in their file and can refer back to it. It can also be useful if there are cover/relief teachers taking any of your lessons – they can have the information without you having to explain it to them.



Introducing James Neilson in 9D

Hi I am James Neilson in 9D. I was born with a genetic disease called cystic fibrosis (CF). It is a non-contagious condition that affects my lungs and digestive system. To look after my body, I have a daily routine of medications, physiotherapy and a diet to suit my needs (which is a bit different to other students). I enjoy school and want to do the best I can but may be away from school at times if I'm unwell and need to spend time in hospital having tune-ups. So here is some information about me which I hope you will find useful:

3. Deciding whether to let friends and classmates know that you have CF

In high school you will make new friends and meet new people. It's up to you whether you tell them that you have CF and when and how much you tell them.

Everyone has a different idea about if and when to tell friends and classmates that they have CF. There is no right or wrong decision. It can be hard to work out what you want to do. Below are some things to consider when you're trying to work out whether or not you will tell others you have CF.

What might happen if you do tell?

- If others know about your CF and you need extra support you have more chance of getting the help you need.
- Sometimes it's easier to be open. You don't have to make up a reason for your cough and medication for example. People will know you cough and need medication because of your CF and it won't be such a big deal.
- If you tell people about your CF you can ask them to treat you in ways that are helpful for you. For example, you can say "Because of my CF I cough more than other people but this is normal for me so don't worry." or "Because of my CF I sometimes have time off from school. Can you please take notes for me if I'm away?".
- If you tell people about your CF you will be able to tell them exactly how it affects you so they don't have to guess, or find information on the internet which doesn't apply to you.

What might happen if you don't tell?

- People won't know you have CF unless you tell them. Your CF can remain private.
- You won't have to answer any questions about what it's like to have CF. Sometimes people ask questions about having CF that might make you uncomfortable or ask you at an embarrassing time. If people don't know you have CF this won't happen.

- If people don't know you have CF they might ask you questions about why you cough or why you need to have medication at school. It can be hard to answer this question if you don't want someone to know you have CF.
- People won't treat you any differently to anyone else, if they don't know you have CF.

Deciding whether to tell people about your CF and when, is something that you will need to do for your whole life. High school is a good time to start working out which choice you feel comfortable with.

Ideas to help you work out what you might want to say

If you have decided to tell your friends and/or classmates you have CF you will need to think about what you want to tell them and how you will do it.

If you aren't quite sure what to say, here are few things you can try.

- Think of 2 or 3 ways that CF affects you which you can easily explain. For example, having lots of chest infections, needing to do treatment and taking medication every day or needing enzymes to digest your food.
- Try explaining CF to your brother or sister or your best friend.
- Ask your parents how they explain what CF is to others.
- Ask your doctor to explain CF to you in a way that you and your friends can understand.
- If you have an older sibling or a friend with CF ask them how they explain it.

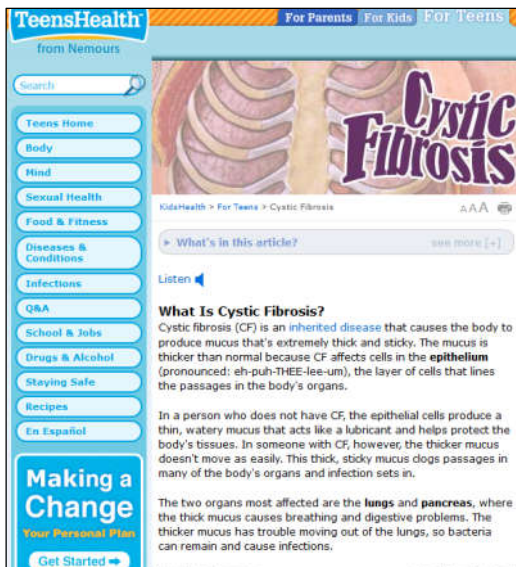
You can talk one on one with people or maybe do a presentation to your class or a Q and A session.

You'll have lots of opportunities to tell people about CF so you don't have to get it perfect first time!

Resources to help you explain about CF

1. You could use some of the ideas from Section 2 or
2. Overview of Cystic Fibrosis (Teens Health Website, USA)

A clearly written overview of CF in 5 sections – What is Cystic Fibrosis, What causes CF, What happens when you have CF, What do doctors do and Living with CF. (Statistics given apply to USA but relevant to Australia).



http://kidshealth.org/teen/diseases_conditions/respiratory/cystic_fibrosis.html#cat20168

3. Sarah's Journey – How does cystic fibrosis affect Sarah (Barts & London Children's Hospital UK)

A good description of the impacts of CF on an 11 year old girl with CF coping with a range of medical appointments and hospitalisations over a three month period. This could be very helpful to explain about what happens to you when you are away in hospital.



<https://www.centreofthecell.org/learn-play/patient-journeys/cystic-fibrosis/?tab=5>

4. Medication at school

Hopefully your school allows you to have your medication with you. It will be much easier for you to have all your medications handy so you can have them when you need to. If your school doesn't want you to keep your medication, they will need educating about how important it is. If you don't feel able to talk to your teachers or they don't listen, your parents or your doctor might have to get involved.

Some people with CF are happy to have medication in front of other people while others are very worried or embarrassed – which is very common.

- How do you feel about having medication in front of other people?
- Do your feelings change with the type of medication it is?



Possible worries and possible solutions:

What will others think or say?

Test the waters by having your medication in front of someone you know well and trust, first. Their positive reaction might help build your confidence.

Being different and being treated differently.

You are different, there's no getting around that. The choice you have is whether to see this as a bad thing, a good thing or just a thing.

You have some power over how people treat you. If someone is treating you well you can reinforce that by thanking them or encouraging that response. If someone is treating you poorly, you can ask them not to.

It might take a bit of time but eventually people will realise that taking medication is just what you do and they will soon overlook it or not even notice.

How do I explain what the medication is for?

Take a few minutes to think up a quick explanation for your different medications so that if someone asks, you can easily think of what to say. Your explanation can be very simple. "I need these so I can digest my food".

5. Keeping healthy

It can be challenging to find time to do everything you need to and want to do. Treatment, medication and exercise can be boring but it's very important that you find ways to fit it all in.

Taking care of your health is so important. Right now, staying healthy will help you do everything you want to do to the best of your ability. In the future, staying healthy will help you achieve further things like gaining qualifications if you choose, finding a job you enjoy, working as many hours as you'd like to, travelling, settling down with a life partner and having children. All this might sound a bit much at the moment, but having CF means that thinking and planning ahead for your future, will ensure that you have more options available to you.

Not taking care of yourself can have negative effects. If you don't look after yourself now you might find it difficult to do everything your friends are able to do. However, sometimes people who don't commit to their treatment and medication don't experience any negative effects until months or even years later. In the future, they might find that their health is not as good as what they want it be and they wish they'd stuck to their treatment a lot more when they were younger.

Tips from students with CF:

"Get your friends involved in exercise – go for a walk, run, swim, bike ride, roller blade, rock climb, surf, dance, lazer tag... the possibilities are endless!"

"Time your chest clearance and nebulisers for when you're watching TV or listening to music so you have some entertainment and incentive. Your parents might even let you watch more TV if you are doing your treatment at the same time! (Plus you may be able to get out of doing certain chores)"

"Organise a reward from yourself or parents for doing your treatments and exercise regularly to give you something to work towards."

"Enroll in a team sport. You'll exercise at practice and matches. Knowing that others are counting on you to turn up will give you another reason to turn up."

"Find a type of exercise that you really enjoy doing. If you enjoy it, you'll be more likely to do it. Just Do It. Do anything. Anything is better than nothing."

"There are lots of different types of chest clearance techniques – chest percussion, PEP, flutter or acapella. If the type you are doing is a real drag, ask your physio if there is another type of chest clearance you can try."

"Routine is great and takes the thinking out of things so try and do your treatment and exercise at the same times each day so you have time set aside."

6. Keeping up with school work

Everyone gets sick and misses school sometimes. You might miss more school than your friends because of doctor's appointments, medical tests or maybe even when you have to stay in hospital. Even when you're at school, you might not feel as well as your friends or have as much energy and time to do all of your school work and extra-curricular activities.

Here are some ideas that might help you stay on top of your work or catch up if you are falling behind.

What you can do

- Start on homework and assignments as soon as you get them and study early for exams. Don't put off getting started. Keeping on top of work can help you avoid feeling anxious.
- Keep taking good care of your health.
- Be creative with school attendance. Perhaps you can have some half days or go to school every second day for a while. These options give you more time for sleep and treatment but you can still go to some classes and see your friends.

Talk to your teachers

- Remember they are there to support you but may not always know you need help – so talk to them and tell them!
- Be proactive and ask for help early on. If you have a lot of work to catch up with, ask them to help you work out which parts are essential to do.
- For times when you are away in hospital or unwell, work out strategies so you can keep in touch with each teacher and with school work. Ask them to send you the work that it is important for you to do.
- Use technology such as Skype, email, recording of lessons, digital resources, photos of board work etc to keep you in touch with what is happening in class.

Talk to your friends

- See if they can help you by taking notes, emailing you resources, having study sessions together or anything else that will help you.

If in hospital

- If you feel well enough, take advantage of the hospital teachers and the facilities.

Tips from students with CF:

"Use your free periods wisely. You can do your homework to give you more time in the evening to relax. You can do some exercise or have a quick nap if you're feeling extra tired." – Andrew

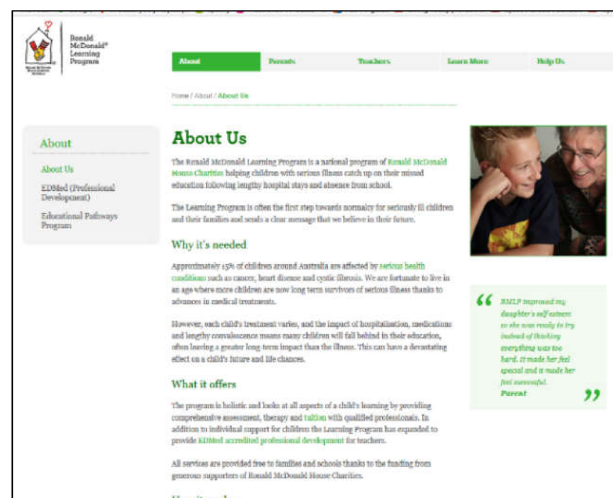
"Ask your friends to share their notes with you and to let you know about any assignments or tests that are handed out if you're away." – Scott

"Talk to your year coordinator about anything that you think might help you. The worst that will happen is that they say no!" – Emily

Other support organisations

Ronald McDonald Learning Program

This is a national program that is part of the Ronald McDonald House Charities which helps young people with serious illnesses such as CF to help catch up on missed education following lengthy hospital stays and absence from school. If you are feeling that you are behind with your schoolwork and could benefit from 1 year of tutoring in a particular subject - have a look at the website with your parents or teachers. You can ask for a year of tutoring in one of your subjects (40 x 1 hour). You are only able to access this once during your education and there can be a waiting list of a few months.



<https://learningprogram.rmhc.org.au/about/>

CFWA and CFCC

Both of these organisations have someone who you can contact to talk about possible resources and options. You can email education@cfwa.org.au or education@cfcc.org.au



7. Keeping connected to friends and support groups

Use technology to keep in touch with your friends

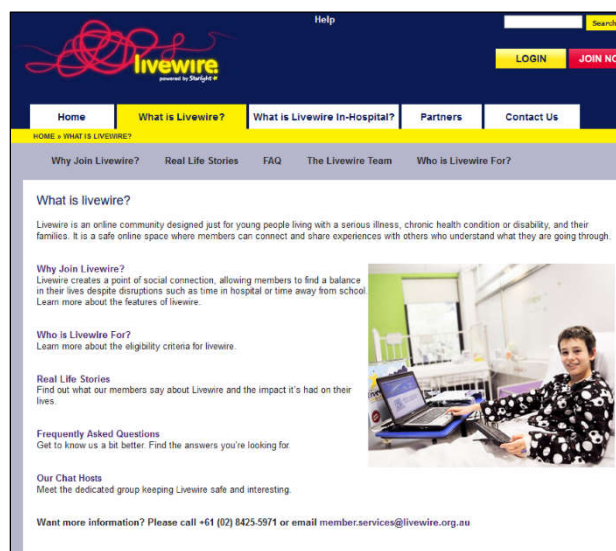
If you are away from school for a while, you may start to feel isolated. Make sure you keep in regular touch with your friends and let them know how important it is to you.



WhatsApp

Livewire

Livewire is an online community designed just for young people living with a serious illness, chronic health condition or disability, and their families. It is a safe online space where members can connect and share experiences with others who understand what you are going through.



<https://www.livewire.org.au>

8. Exams

Exam time is not always fun! A lot of hard work goes into getting a mark you're proud of. CF can make exam day more difficult. There are lots of reasons CF could interfere with your exam performance. If you're feeling unwell on the day you might find it difficult to concentrate as well as you normally do. You might be distracted by having medication or food during the exam or you might have an upset stomach because you didn't get your Creon dose right the day before.

Exams in Year 7 – 11

In Years 7-11, the school can put in some adjustments to ensure you perform to the best of your ability. Reasonable requests, based on typical CF symptoms may include:

- Giving additional time to complete the exam to make up for the fact you are coughing a lot, or rest breaks to help regain your concentration.
- An individual room to take away the worry of coughing lots in the big exam hall!
- An exam room close to toilets or one where you can change the air conditioning.
- Being able to bring in food, drink and medication into the exam
- The possibility of doing a make-up exam if you're away on the exam day.

- Doing the exam at home or in hospital.

If you think these options would be helpful, talk to your parents and your year coordinator about what they can do to help you. The requests will need to be discussed in advance.

Exams in Year 12

In Year 12 you can definitely have special exam provisions for your final exams. Extra time, an exam room on your own which is close to the toilets, availability of food, drink and medication, rest breaks and more are available to you. Remember, Year 12 exams are often as long as 3 hours and you may be sitting 2 in one day! For this reason it's important to think about how you might cope under these demanding conditions.

Applications for special provisions need to be arranged early and you will need specialized medical documentation, so if you want to explore these options talk to your parents and Year coordinator sooner rather than later so you don't miss out.

If you do decide to apply for special provisions, be sure to keep a copy of any medical documentation you collect as this might be helpful if you want similar provisions later on at TAFE or University.

You might not want or need any extra help. Just remember that if you are unwell on the day these allowances can help you do your best.. You don't have to use the special provisions but having them available to you IF you need them might be helpful.

Career planning

It's worth thinking about what you might want to do in the future when you are choosing your Year 11 and 12 subjects. Your school may have a careers advisor you can talk to. There are some jobs which people with a chronic health condition may not be able to apply for, such as the armed forces, the police force, a firefighter or a paramedic. Check directly with any such organisation to confirm this. There may be other roles within the organisation that are more suitable. Other than these few types of jobs, there is no reason why CF should hold you back from pursuing the career of your dreams. People with CF do all sort of different jobs so it's definitely possible to find a career that you enjoy that can fit in with your health needs.

Tips from students with CF:

"At first I didn't see the point of organising special provisions for my Year 12 exams but my parents made me. In the end I was actually really glad. I didn't use most of them (like toilet breaks or extra time) but it was really good to know I had those options if I needed them." – Anna

"I liked doing my exams in a small room with only a couple of other students. It didn't seem as full on as in the big hall with hundreds of students." – Matt

"I organised special provisions in Year 12 which were great. I wish I had known I could have asked for these things earlier in high school." – Tom

Some people will suggest that certain jobs are less than ideal if you have CF. For example, being a baker who constantly works with flour dust in the air, a labourer who always needs to be physically strong and fit and work in extreme weather conditions or a doctor who works very long hours would not be ideal for your health. However, there are bakers, labourers and doctors out there who have CF.

When thinking about a career, you might want to consider a few more things to make sure you pick a job which suits your health best. Choosing a career which helps you stay as healthy as possible means you will enjoy it even more.

Here are some things to consider:

- Jobs involving chemicals, particles in the air or strong odours may aggravate your lungs.
- Jobs requiring very long hours may make it hard to fit in medication and treatment or mean that you don't have enough energy to stay well.
- Jobs requiring a lot of physical energy and strength might be too demanding when you are feeling unwell.
- A flexible employer will be helpful for time off for doctor's appointments and possible hospital admissions.
- You may wish to work part time at some point so a career which accommodates this would be ideal.
- If you are self-employed you may have more flexibility when unwell but you may find that if you aren't at work, you aren't getting paid.
- Being able to work from home may give you more time in your day for treatment, medication, exercise and rest

9. Further study

Special Entry/Equity schemes and Scholarships

Some universities and TAFE's offer special entry or equity schemes which can help you get into the course you want. These schemes take into consideration factors such as illness, financial hardship or other issues that might have stopped you getting the marks you would otherwise be capable of.

Talk to your parents and year coordinator early if you wish to find out more information. To get the right information, you might want to contact the tertiary education provider directly to enquire whether they participate in such schemes. The schemes and acceptance criteria differ in each state and territory.

You might feel that you don't need or want help to get into the course you have selected. However, knowing you have some help available if needed, can stop you missing out on your next educational milestone. After all, consider all the extra study you could have done if you weren't so busy taking care of yourself and your CF! It's only fair that this time is recognised through such equity schemes, especially if CF has prevented you from performing at your best.

In some states, university admissions centres may grant additional "bonus points" to allow you to enter a course with a lower cut-off than the Year 12 mark you received. For more information, you or your teacher will need to approach the university admissions centre in your state or territory as they will have different criteria.

You can also apply for scholarships on equity grounds too! For more information, do a search for "equity scholarships" through your state or territory's universities admission centre or contact the university you're interested in attending .



www.cfsmart.org

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