EDITIONFOUR 2015

RED magazine

IN THIS ISSUE

MENTAL HEALTH AND WELLBEING

RED

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ON THE COVER
Ben and Taj Daniel

Mental Health and Wellbeing

The ageing of the CF population is rightly seen as a triumph of the multidisciplinary-team approach to treating CF.

Not so many years ago, issues like family planning, retirement and career development didn't even make it onto the agenda for a person with CF. Now we celebrate these issues as we embrace the new phenomenon. Never have we had more hope for the future than we have today. With the advent of new drugs and treatments we can confidently expect this trend to continue into the future.

However in addition to the opportunities that the ageing population presents comes a whole new set of challenges. CF-related diabetes and mental health issues are becoming more commonplace and we see a rise in demand for these services.

The theme of this issue of RED magazine is focussed around mental health. It was not so long ago that people with mental health issues faced a significant stigma and prejudice in society. This was based largely on ignorance. Whilst this ignorance still exists today, it is far less common than it used to be and mental health is rightly seen as a mainstream health issue to be proactively managed.

On the research front, we have exciting news about how one of our researchers is working to combat persistent infections using nitric oxide and some amazing insights into how bacteria are working together to defend themselves. This research has the potential to offer real benefit, not only to people with CF, but to the wide population who are increasingly having to deal with antibiotic-resistant infections.

Nigel Barker, CEO

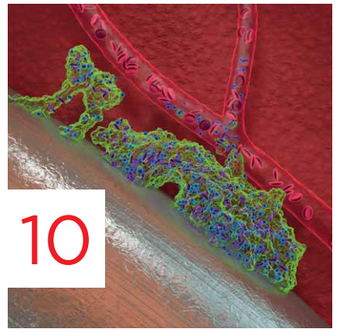
Fundraising for services and research remains a vitally important part of our activities. You can share in our success by getting involved as an individual or a group as we continue to stride towards our goal of Lives Unaffected by CF.

In this last edition for 2015, may I take this opportunity to thank each and every one of you that have supported us in 2015. Together, we have had a truly wonderful year and I am confident that together we will build upon that success in 2016.

Thank you.

RED NEXT EDITION
If you would like to contribute to the next edition of RED please email marketing@cysticfibrosiswa.org for more information.

CONTENTS



10

MICROBIAL MONSTERS

ANXIETY AND DEPRESSION

12

14

CF AND BODY IMAGE

FUNDRAISING NEWS

30

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FEATURES

HEALTH & RESEARCH

4 > CFA Update

5 > Conference Lay Program Now on Video

6 > Psychosocial Aspects of Lung Transplantation in the Cystic Fibrosis (CF) Population

8 > PHD Top Up Scholarship

9 > Using Your Skills, Knowledge and Experience to Improve Your Child's Health (or Your Own)

10 > Microbial Monsters

12 > Anxiety and Depression

SERVICES & EVENTS

14 > CF and Body Image

17 > Sibling and Offspring Camp

18 > Interview with Michael Cahill

20 > Interview with Elliot and Ian Anderson

22 > Interview with Guy and Lisa Daniel

23 > Mental Health Support Services

24 > RED Resources

26 > Supporter Spotlight - Tim Cash

28 > Cross Country Ride for a Cure

29 > 2016 Parents' Retreat
> Farewell Denise Cork

FUNDRAISING NEWS

30 > Fundraising News

33 > US Generosity Extends Helping Hand to CFWA

CF CORNER

34 > CF Diary
> Spanish Omelette

35 > Questions About Living with CF

CFA Update

Exciting Times in Cystic Fibrosis Research

Nettie Burke,
CEO CFA

In August this year, the Trustees for the Australian Cystic Fibrosis Research Trust (ACFRT) signed a contract with the University of Wollongong (UOW) for a research project called ***'Multi-action antibiotics to treat chronic biofilm infections'.***

The project has been peer reviewed to 'World's Best Practice' by the National Health and Medical Research Council's review process and the ACFRT has committed to fund the project to $588,687 over three years.

Biofilms often build up in the lungs of people with CF and these biofilms contain large populations of bacterial cells and are encapsulated within gum-like materials.

Biofilms protect bacteria against the action of antibiotics and against the action of cells in the patient's immune system. Antibiotic resistance can be increased up to 1000-fold in biofilms.

The Chief Investigator for the Project is Dr Michael Kelso from UOW and he and his research team were the first to discover that low concentrations of nitric oxide (NO) act as a signal that triggers bacteria in biofilms to disperse so that the bacteria become much more sensitive to antibiotics and the body's immune system.

When the researchers combined the use of NO-releasing compounds with antibiotics, they developed a new way of targeted delivery of NO to biofilms.

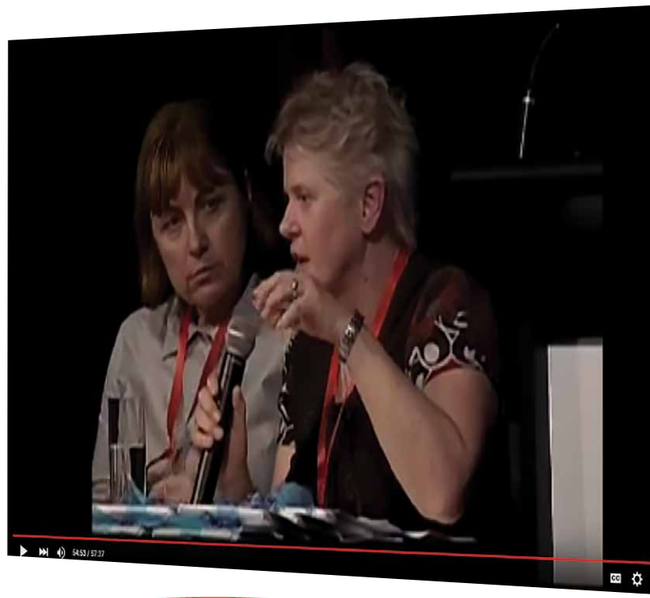
The aim of this research project is to formulate and evaluate a new generation of compounds with higher potency antibiotic activity that retain their ability to release NO when they encounter biofilms. Those compounds that appear most promising will undergo comprehensive safety testing prior to efficacy testing in animal models.

Cystic Fibrosis Australia is extremely excited about this research project and will provide updates on Dr Kelso work over the next three years.

Conference Lay Program Now on Video

www.cysticfibrosis.org.au/conference

Following another informative lay program at the 11th Australasian Cystic Fibrosis Conference, those who were unable to attend can view proceedings online. The variety of information and topics was broad and video published to date covers a wealth of subject matter.



- *Reproductive health and wellbeing* - Sue Towns
- *Perspective, the development of CF care in Australia, where are we going?* - Claire Wainwright
- *Participate! Using your skills, knowledge and experience to improve your childs health* - Susan Biggar
- *Medicines for children with CF* - Courtney Munro
- *Maximising nutritional outcomes facts and fiction* - Francis Hollander
- *Sexual health in adolescents with CF* - Jude Morton and Katherine Frayman
- *CF screening for everyone understanding population based CF carrier screening and CF carrier testing for relatives* - John Massie
- *What will the future bring us? How can we plan?* - Peter Wark
- *Travel - removing the barriers to live life free* - panel discussion
- *Understanding bugs, infections in CF* - Pardeep Singh
- *Growing up in a CF world, transitioning with success* - Jude Morton

Additional presentations and papers will be published on the same website as permissions are acquired so be sure to check back in the coming months.

Psychosocial Aspects of Lung Transplantation in the Cystic Fibrosis (CF) Population

Notes from the 2015 Australasian CF Conference presentation by Jane Harris (Social Worker) and Carla Patist (Psychiatric Registrar) from the Lung Transplant Service, Alfred Health, Melbourne.

Lung Transplantation History:

- Lung transplantation began at The Alfred Hospital in 1983
- Since then 1,200 lung transplants have been performed in total
- In 2014, 84 lungs transplantations were performed
- The Alfred Hospital performed the world's first Bilateral Lung Volume Reduction Surgery (BLVRS)
- The average waiting time for a lung transplant at The Alfred is 90 days
  - Some wait longer, e.g. small women

*Referrals are encouraged earlier rather than later. Initial referral assessment for lung transplant is usually performed as an inpatient and takes approximately 3 days at The Alfred Hospital.

Considerations for Transplant Eligibility:

- Concurrent adherence to treatment regime
- Ability to co-operate with the treatment team
- Good Support system
- Substance use or dependence, e.g. alcohol, tobacco, marijuana, etc. If this is an issue 6 months abstinence is required.

Goals of a Psychosocial Pre-Transplant Evaluation:

- Promoting fairness and equal access to care
- Maximising optimal outcomes and wisely use scarce resources
- Ensuring that the potential for benefits outweigh surgical risks to the patient by identifying potential risk factors (i.e. substance abuse, compliance issues, serious psychopathology) that may result in increased risk of postoperative complications leading to transplant failure.
- Providing information to develop treatment planning for individuals at high risk:
  - Identifying patient's level of neuropsychiatric and cognitive functioning
  - Developing a psychiatric treatment plan to address current psychiatric problems and help minimise preventable problems
  - Implementing appropriate treatments that reduce harm and mitigate risk

Psychosocial Assessment:

- History
- Stanford Integrated Psychosocial Assessment Tool (SIPAT)
- Family
- Social circumstance
- Coping skills
- Psychiatric illness

Psychosocial Domains and Factors Measured by the SIPAT:

(A) PATIENT'S READINESS LEVEL AND ILLNESS MANAGEMENT

Item 1: Knowledge and understanding of medical illness process (that caused specific organ failure)

Item 2: Knowledge and understanding of the process of transplantation

Item 3: Willingness/desire for treatment (transplant)

Item 4: History of treatment adherence/ compliance (pertinent to medical issues)

Item 5: Lifestyle factors (including diet, exercise, fluid restrictions, and habits according to organ system)

(B) SOCIAL SUPPORT SYSTEM LEVEL OF READINESS

Item 6: Availability of social support system

Item 7: Functionality of social support system

Item 8: Appropriateness of physical living space and environment

(C) PSYCHOLOGICAL STABILITY AND PSYCHOPATHOLOGY

Item 9: Presence of psychopathology (other than personality disorders and organic psychopathology)

Item 10: History of organic psychopathology or neurocognitive impairment (i.e. illness or medication-induced psychopathology, anxiety, panic attacks)

Item 11: Influence of personality traits vs. disorder

Item 12: Effect of truthfulness vs. deceptive behaviour

Item 13: Overall risk for psychopathology

(D) LIFESTYLE AND EFFECT OF SUBSTANCE USE

Item 14: Alcohol use, abuse, and dependence

Item 15: Alcohol abuse - risk for reoccurrence

Item 16: Illicit substance, abuse and dependence

Item 17: Illicit substance abuse - risk for reoccurrence

Item 18: Nicotine use, abuse, and dependence

Long-Term Issues Post-Lung Transplant:

- Psychological issues:
  - Adjustment, body image, eating disorders
  - Mood disorders
  - Post-traumatic stress disorder
  - Survival guilt
- Sexuality/fertility
- Work
- Non-compliance 25-30%
- Rejection
- Re-transplant
- Transplant-palliation

REFERENCES:

Maldonado, J., Dubois, H., David, E., Sher, Y., Iolak, S., Dyal, J., & Witten, D, (2012). The Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT): a new tool for the psychosocial evaluation of pre-transplant candidates, *Psychosomatics*, 53:2, 123-132.

PhD Top Up Scholarship

Supporting mental health and quality of life for infants and children with cystic fibrosis (CF) and their families.

Cindy Branch-Smith of the Telethon Kids Institute.

Early Surveillance for CF Lung Disease

We wanted to know what parents experience and how they cope with their child's early surveillance medical procedures. The medical procedures are conducted annually and include a bronchoscopy, a low-dose chest CT scan under general anaesthetic, and infant lung-function testing under sedation for babies under two years of age.

Parents expressed significant anxiety about their child's medical procedures and about receiving the test results. Parents were concerned about what the test results would show and what they mean for their child's short-term and long-term health. Parents also said they sometimes felt self-judgement because they perceived any progression of lung disease as a failure on their part as the primary parent/carer for their child.

Even though parents understood the variable nature of CF progression, they couldn't help but feel responsible. Therefore, we need to provide support to parents in understanding that early surveillance results may make them feel this way, and that it is a normal reaction.

Parent Mental Health in the First Six Years of a Child's Life

We wanted to characterise our population of parents whose children undergo early surveillance so that we have a comprehensive picture of what it looks like to have an infant or young child with CF in Western Australia. Families appear to cope well, however, we know that parents can struggle to accept and adapt to their child's diagnosis, and to make the rigorous treatment regime a routine within the family lifestyle. We looked at a lot of family characteristics to understand what family life is like.

Some concerning results came up about parent depression, anxiety and stress. We also looked more closely at parenting stress, and we found that parents who have a child with CF are twice as likely to experience parenting stress than the normal population.

Clinicians and researchers have a duty to provide the best care we can to our patients, and we feel that supporting parents is one way we can do this. Therefore, we will endeavour to reduce parent mental health issues as part of our support program.

New Project – Supporting Young People with CF at School

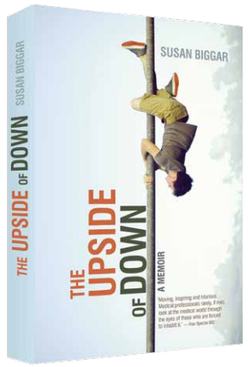
Medical and treatment advancements have meant that people born with CF in the past 20 years are expected to live well into their 40s and 50s. Therefore, academic achievement is important for their long-term outcome. Negative school experiences of young people with CF can affect their developmental outcomes. Such experiences can increase social isolation, diminish academic achievement and peer relationships, and increase risk of mental health problems.

Thus far, efforts to support young people with CF in the school environment have been limited. This research study will use online techniques to engage young people with CF and their families as co-researchers to develop and pilot a support program. An online survey of psychosocial and school experiences with young people and their families will guide online discussion forums that aim to facilitate development of an online intervention. This means that young people with CF will engage with researchers to develop the intervention. This modern approach to intervention development aims to improve social, mental and emotional health needs and school engagement and achievement outcomes of young people with CF.

We will soon be contacting young people aged 10-16 years and their families to see if you would like to take part in this new and exciting research project. We also want to include parents and young people in the direction of the study which involves meeting with the research team and discussing ideas about the research.

If you are interested in joining our stakeholder committee as a consumer representative, please contact Cindy Branch-Smith on 08 9489 7822.

Using Your Skills, Knowledge and Experience to Improve Your Child's Health (or Your Own)



2015 Australasian Cystic Fibrosis (CF) Conference presentation by Susan Biggar, parent of two CF adults and author of "The Upside of Down, A Memoir."

The quality of healthcare that children with CF receive really does matter. As reported by Atul Gawande, a US based surgeon, in his article "The Bell Curve", the average life expectancy differs in CF clinics across the US. Different clinics provide different quality healthcare and have different health outcomes for people with CF.

Being an active participant in your child's healthcare can improve the health outcomes for your child.

The key findings of the US CF Foundation Clinical Practice Benchmarking Project was that the centres with the best clinical outcomes had the following features:

1. Systems

- Strong leadership
- Dedicated multidisciplinary team
- Easy accessibility by patients and families
- Close tracking of clinical details and outcomes

2. Attitudes

- High expectations for pulmonary and nutritional status
- Low threshold for vigorous treatment of health declines
- Aggressive use of antibiotics for pulmonary symptoms
- Team consensus on standard approach to care

3. Practices

- Pre-clinic review of patients and treatment planning
- More frequent clinic visits for identified health concerns
- Regular patient visits with full multidisciplinary team

4. Patient/family engagement and empowerment

- Patients provided with data on their clinical outcomes
- Patients/families educated on high outcome expectations and need for early, aggressive intervention for declines
- Patients/families encouraged to provide feedback on their clinical care experiences and concerns

5. Projects

- Self-assess programme outcomes and practice patterns
- Develop projects to improve programme performance of key clinical practices

How to participate (as a parent):

- Believe in yourself
- Learn - what do I need to know to do my job of caring for my child better and how am I most likely to learn this? Let knowledge be a friend not a foe
- Ask, ask, ask
- Be vigilant – we should never tolerate a deterioration of lung health
- Remember, guilt doesn't help us but opportunity does

Participate together on system wide issues:

- Link up with others
- Think broadly
- Focus on what you know
- Pick your issues carefully, e.g. is the issue winnable and will it result in improving the outcome for my child's health?

Action plan for parents:

- What are the issues that matter most to me?
- What are two realistic things I could do to try and improve them?
- Who could help me do this?

Improving the quality of care your child receives is possible by being an active participant in their healthcare. Change is possible with persistence and dedication.

REFERENCES:

Biggar, S. (2015). Australasian Cystic Fibrosis Conference proceedings - Participate! Using your skills, knowledge and experience to improve your child's health (or your own), Sydney August 16, 2015

Boyle, M., Sabadosa, K., Quinton, H., Marshall, BC & Schechter, M. (2014). Ten years of improvement innovation in cystic fibrosis care: key findings of the US Cystic Fibrosis Foundation's clinical practice benchmarking project, British Medical Journal, 23: i15-i22. com/2015/03/12/the-cellular-mechanism-of-cf-the-basics/

Microbial Monsters

From an original article by Bronwen Morgan

The Australian Cystic Fibrosis Research Trust (ACFRT) managed by CF Australia, is currently looking at how nitric oxide might be used effectively to break down biofilms so that antibiotics can be more effective in treating infections. Whilst a paper on this research will appear in a future edition of RED magazine, the following article explains a little more about biofilms and why have they garnered so much interest recently.

Who can forget Superman? Christopher Reeve embodied the superhero – in films and in life. When he fell from his horse in 1995 while training for an equestrian event, Reeve was left quadriplegic but undefeated. Ultimately, this super man was beaten by a microbial infection and Reeve passed away on October 10, 2004.

It was probably not a superbug that brought down Superman. More likely it was a microbial monster of a different kind. A biofilm bears little resemblance to the individual rods or sphere-shaped cocci traditionally studied in biology class. It's much more like a living animal composed of multiple cell types – bacteria, archaea, fungi, yeasts – communicating and working together. That makes biofilms almost bullet-proof when it comes to antibiotics. They cooperate to create a near invincible slime shield.

The Canadian microbiologist William Costerton an avid mountaineer, hoped to combine his passions to study the microbes of mountain streams. What he found surprised him. The fast flowing waters were almost sterile, yet the rock that caused his undoing was colonised with slime-forming bacteria.

Though biofilms were well known from marine environments these ones got Costerton thinking. If bacteria could gain such a tenacious foothold in a fast-flowing mountain stream, how might they behave in the human bloodstream?

For ever microbiologists had pictured bacteria as floaters, existing in a "planktonic form". But thinking about the slimy films, Costerton began to ask if these types of microbial colonies could explain some of the more persistent infections of the human body. He thought of the lungs of his son who suffered from cystic fibrosis – they also appeared to be covered in a slimy bacterial layer. In 1977, Costerton attended a meeting on lung infections in cystic fibrosis in Montréal. There he met Danish physician and cystic fibrosis specialist Niels Høiby, who had also been studying the clumps of slimy bacteria from the sputum of his cystic fibrosis patients. "I'd never seen anything like it," he recalls. "The clumps resembled frogs' eggs." He proposed the slime might be the reason immune cells could not clear the infections.

Høiby and Costerton formed an alliance to raise medical awareness of this microbial phenomenon. Costerton was a great communicator and played the lead role. When Costerton he passed away in 2012 he was known as the "father of biofilms".

Cynthia Whitchurch based at the Ithree Institute at the University of Technology, Sydney, is pursuing the interest that captivated her since doing her PhD. How do bacteria move en masse across a surface?

How do the individuals coordinate their behaviours? One insight came in the 1990s with the discovery of how *Vibrio fishceri*, a luminescent bacteria that lights up the underside of the Hawaiian bobtail squid, coordinates its behaviour. Balmy Hawaiian nights may be brightly lit by moon or star light so the squid needs counter-illumination if it is to stealthily hunt the creatures swimming below. But the low densities of *Vibrio* found in the ocean do not glow. Much as a committee will not vote until it reaches a quorum, *Vibrio* first needs to reach a density of 10 billion cells per millilitre of water before it casts a light. Their breeding ground is a cavity on the underside of the squid called the light organ. (It also has shades in case the night is cloudy.) Each evening the bacteria reach the necessary quorum and begin to luminesce. Each morning the squid turns downs the wattage by venting the Vibrio, perhaps to save nutrients. It's an extraordinary story but what intrigued the microbiologists was how did free-living bacteria, supposedly oblivious to each other, sense each other's presence? "To me the most fascinating understanding is that they can talk in order to co-ordinate their functions," says Whitchurch. That mechanism, dubbed "quorum sensing", is also key to the formation of biofilms.

When microbes hit a tooth or an artificial hip they attach within minutes. They send signals to recruit others, and once they sense a quorum, work to build a matrix. Within hours it encases them like a slimy tortoise shell which can account for 90% of the mass of the biofilm. Quorum sensing also cues the bacteria to release toxins en masse – solo actors would do far less damage.

Studying biofilms that form at the interface between agar and plastic using time-lapse photography, Whitchurch has observed these films march forward like a phalanx. But the microbes also act like organisms far higher up the evolutionary tree. Like sponges they work together to build complex structures. Within days, small microbial villages may become cities that are millimetres thick and replete with tower blocks and water-filled channels to supply nutrients and remove waste. Individual bacteria can take on specialised roles be it to produce building blocks for the shield or maintain surface attachment. "They talk, they build; they're civil engineers. It's an amazing time to be a microbiologist,"says Whitchurch. When the biofilm becomes overpopulated or nutrients become scarce, they also release multiple explorer microbes that are carried away by the current.

Whitchurch also stumbled upon another revelation about biofilms in 2002. The slime that encases the film is a complex goo. Costerton referred to it as the *glyocalyx*, reflecting the understanding that it was primarily made of sugars. Now it's been dubbed the Extracellular Polymeric Substance or EPS to connote that it's more of a dog's breakfast – not only a variety of long sugary molecules but also bits of proteins, lipids and even snippets of DNA. This "extracellular" DNA (eDNA) was thought to be refuse, threads of DNA extruded as dying cells burst. But the vast quantity made Whitchurch question that, so she added an enzyme that dissolves DNA to the biofilm. To her amazement, the biofilms shrank. The simple experiment ended up as a ground-breaking publication in the journal Science. It turns out the structural properties of the double helix are exploited by biofilms, especially to reinforce their slime shield. A DNA-dissolving drug (Pulmozyme) has been used in cystic fibrosis patients to help disrupt the biofilm.

The DNA reinforced slime barrier is only part of the explanation for how biofilms can be up to 10,000 times more resistant to antibiotics than bacteria in the planktonic form. For one thing, most antibiotics throw a spanner in the works of dividing or metabolising cells but it turns out mature biofilms harbour dormant spore-like cells in their interior. So any antibiotics that do penetrate the biofilm will not be able to eradicate the so-called "persisters". Administering low levels of antibiotics can also backfire. The survivors activate stress-response genes that see them building bigger and more robust biofilms. The members of a biofilm are also immersed in each other's DNA, allowing for a never-ending swap meet – a challenge when some of the participants carry antibiotic-resistant genes.

Microbiologists have long been aware of the so-called horizontal gene transfer. The new understanding of biofilms explains why this is so prevalent.

Biofilms also foil the immune system. And not only by means of their impenetrable slime. In 2007, Høiby's team observed a contingent of immune cells zero in on bacteria – then they saw an ambush. Poking out of the biofilm was a war machine built of sugars and lipids. Called a "rhamnolipid canon" it blasted holes in the immune cells, a strategy coordinated by quorum sensing.

Unable to clear nasty biofilm infections, immune cells congregate on the outskirts and continue to mount their blunted attack. The toxins, like free radicals, fired at the biofilm end up damaging the surrounding healthy tissue. So, explains Høiby, biofilm infections in cystic fibrosis patients end up destroying lung tissue; in artificial knee joints they eat away at the bone. And biofilm infections in the stomach, colon, liver and prostate are associated with the development of cancer.

Yet biofilms aren't all bad. Most of our resident bacteria, our microbiome, resides in biofilms – they are essential to our health. Problems occur when a particular biofilm ecosystem becomes imbalanced.

Meanwhile, the war against bad biofilms needs to be won. Researchers have been like espionage agents, stealing biofilms' battle plans and cracking their communication codes. And Randy Wolcott's patients have been benefitting.

The more recent gels include hamamelitannin, an extract of witch-hazel bark that inhibits quorum sensing. Other biofilm-specific treatments that block the communication codes are waiting in the wings. While the biofilm is a mixture of different species, it is no Tower of Babel. A chemical called cyclic-di-GMP is a universal signal for bacteria to aggregate. Last year, Høiby's group showed they could disperse a *Pseudomonas aeruginosa* biofilm growing on silicone implants in mice by decreasing the levels of cyclic-di-GMP. Very low concentrations of the gas nitric oxide also act as a dispersal signal for many bacterial species.

The hope is that biofilm-based tactics will disseminate fast. Not only could hundreds of thousands of lives be saved, but we might stop our headlong descent into the "end of antibiotics era". As Wolcott put it "the 'one and done' strategy of treating infections as if they are planktonic is not and cannot work for biofilm". But he adds "the good news is we can accumulate new knowledge faster than the bacteria evolve".

This article is based on an article written by Bronwen Morgan that first appeared in Cosmos Magazine in June 2015 *www.cosmosmagazine.com* reproduced by kind permission of Cosmos Magazine.

Images courtesy of Chris Hughes / DMAX / Cosmos Magazine

Anxiety and Depression

A large study of 6000 patients and 4500 caregivers from nine different countries (M, Boyle & A, Quittner, 2013) indicated that the occurrence of anxiety and depression was 25% higher in adolescents with cystic fibrosis (CF) than the average population and 35% higher amongst care givers.

REFERENCES:

Boyle, M & Quittner, A. 2013. Defining depression and anxiety in cystic fibrosis, Medscape Education Pulmonary Medicine.

(http://www.cff.org/UploadedFiles/research/ClinicalResearch/PatientRegistryReport/2012-CFF-Patient-Registry.pdf)

This rates as the third highest co-morbidity amongst people with CF. Anxiety and depression can be episodic, lasting for short periods and associated with specific triggers e.g. a specific medical procedure, which is a normal stress reaction, however for some these feelings continue affecting our ability to enjoy life, manage relationships and health.

WHAT TRIGGERS ANXIETY?

New CF diagnosis:

Although prognosis is now very positive for people born with CF today, for most parents receiving news that your baby has CF is a traumatic event. The trauma of diagnosis generally becomes bearable with increased confidence to manage treatment, however, for many, what is experienced is chronic sorrow. This is a normal grief response experienced by both men and women with a chronic illness and their care givers. It is associated with an ongoing living loss that is permanent, progressive, recurring and cyclic in nature. It is different to normal grief as there is often no resolution and stages of grief can continue, particularly at times of stress, e.g. hospitalisation.

"Any dream of a happy "white picket fence" existence is definitely gone. At some level you're mourning the loss of a typically developing child all the time. You get up every day not knowing what will happen" (Parent)

Other Triggers:

For people with CF and their care givers the following triggers can also contribute to stress, sometimes leading to ongoing issues of depression and anxiety:

Health changes and/or deterioration

- New diagnosis e.g. CF related diabetes (CFRD), continence issues, low lung function
- Difficulty maintaining normal activities such as work and relationships
- Poor body image
- Lung transplant and/or fear of death

Hospitalisation

- Needle phobia and fear of invasive surgery
- Bad news, e.g. new bug, lowered lung function
- Haemoptysis or pneumothorax in past six months

OUTCOMES OF UNTREATED ANXIETY AND/OR DEPRESSION:

- Poor adherence to treatments (approximately less than 50% for adolescents and young adults).
- Reduction in parent's ability to routinely administer medication and other treatment to their children.
- Reduction in children's ability to cope. Research shows a direct correlation between parental anxiety and depression and children's ability to cope.
- Inability to understand treatment regime.
- Decreased quality of life:
  - poor relationships
  - lower self-esteem
  - poor body image
  - lack of engagement in the workforce
  - low motivation
  - risky behaviour/s
- Increased hospitalisations and healthcare costs.
- Inability to stay on track with treatment regimens and consequently worse health outcomes. Research indicates a direct correlation between good mental health and adherence to treatment.

WHAT HELPS?

There are obvious things that help with chronic stress such as daily exercise, good diet, adequate sleep, relaxation and fun activities, but sometimes it's difficult to find the motivation to even do these things.

You're not alone. Everyone struggles at times to stay motivated and positive. Acknowledge that there will be difficult times and developing good strategies to manage is important.

"You have to think that everybody with CF will, at some time, feel anxious and/or depressed". (Female, 32)

TIPS ON BALANCING CF AND MENTAL HEALTH

(Reprint interview excerpt: Holly Ralph, adult with CF):

"Primarily it's important to remind myself frequently that I am not my disease. It is a facet of my life but that I am much MUCH more than that. I try to maintain balance by realising that I can do (nearly) all things but that I can't do all things at once. For example, I may spend a few months where I socialise more, but then the next few months I'll socialise less and pick up more work. What's not negotiable? Treatments and sleep! As soon as I start scrimping on sleep my health starts to decline".

"If I have a decline in my physical health it also affects my mental health, and I feel sad, flat and unmotivated. It's harder to exercise and do treatments, because I'm tired and feel 'crappy', so my health can rapidly begin to spiral downwards. That's where I find it's really important to fall back on discipline around treatments and exercise. Discipline trumps motivation every time. Motivation waxes and wanes, you can't depend on it!".

"For me, recognising when I'm becoming unwell, and going into hospital early works really well. I improve quicker and my mood stays higher. The sooner I get into accepting that I'm unwell, having a little cry and then pushing on and admitting myself to Charlies, the quicker that I can get back to the sweeter aspects of my life".

MINDFULNESS-BASED STRESS REDUCTION

This program has been recommended by a number of people with CF and others who suffer from chronic pain, addiction, anxiety and depression. This program was originally developed by Dr Kabat-Zinn utilising a combination of meditation techniques and cognitive-based therapy. This includes: mindfulness meditation, body awareness and yoga to help people become more mindful, staying in the present moment. People are also coached to respond better to reactive thoughts and not get caught up in a negative spiral of thinking.

There are currently lots of published papers on the benefits of mindfulness and programs are now offered in hospitals and community centres internationally. With focused practice it is seen that the structure of the brain can actually change. The areas of the brain associated with empathy, emotions and compassion grow, while areas involved in anxiety and stress shrink. Therefore, it is believed this practice can help to foster emotional balance and self-compassion for ourselves in times of stress.

If you are struggling with anxiety and/or depression there are numerous supports as listed in the RED resources section, however, you can also ask to speak with the social worker from your respiratory team or contact Kathryn at CFWA servicesmanager@cysticfibrosiswa.org or on 08 9346 7333.

HERE ARE SOME RESOURCES YOU MAY FIND USEFUL:

Mindfulness Based Cognitive Therapy®
www.mbct.com/about/how-will-mindfulness-practice-help-me/

There are also a number of workbooks, guided meditations and community-based programs available.

TEDx Talks®
www.tedxtalks.ted.com/video/Learning-to-die-%7C-Carly-Jay-Met

Features a worthwhile link from Carly-Jay, an adult with CF from Queensland talking about how she has managed extreme stress.

Smiling Mind®
www.smilingmind.com.au/my-smiling-mind/

Has FREE web and app based guided meditations for all age groups.

Sick and Happy®
www.sickandhappy.com/category/wellness/

This is another good website with great articles on developing emotional resilience.

CF and Body Image

A recent Paediatric Pulmonary Journal by Simon et al (2011) indicated that more than a quarter of CF adolescents were dissatisfied with their bodies.

Weight:

Self-perceptions of body satisfaction can be directly related to nutritional adherence and respiratory health. Females are particularly at risk with almost 45% of girls reporting much lower levels of body satisfaction than males, due mostly to the desire to be thin whereas males have a preference to be heavier with more muscle. There is also a similar perception amongst adults with CF, however, adolescents are at even greater risk of poor dietary intake due to their increased energy requirements and non-adherence to medical regimes.

Many people with CF often feel under pressure to eat and maintain weight:

"Around age 16, I really started to resent the constant pressure to eat and constant monitoring at hospital visits. I think at that point some of the pleasure of eating disappeared." (Female, 31)

As presented at the 2015 Australasian CF Conference in Sydney, the Adult CF Centre (ACFC) at the Prince Charles Hospital in Brisbane reported growing concerns around obesity amongst a traditionally underweight population of people with pancreatic insufficiency. This is due to much improved treatment regimens, including new medications such as Kalydeco®. The ACFC reported 6% of patients experiencing a Body Mass Index (BMI) over 30 (clinically obese) with 50% of those being pancreatic insufficient.

People with overweight issues have a different set of body issues to deal with:

"I have suffered from feeling overweight for a few years now. Although I'm glad I don't look 'ill' I often feel overlooked because of this. My lung function is only 38% at best and I don't think people notice how hard life can be because I don't look like I'm struggling." (Female, 17)

Weight Quick Tips:

- ☐ Develop healthy/dietary goals with your dietitian and/or respiratory team; this may be a compromise between the both of you
- ☐ Set small goals that are achievable
- ☐ Find someone to talk to in the team, or a counsellor, if you are having trouble with body weight issues
- ☐ Talk with your dietitian about some healthy alternatives if you're worried about a high fat diet
- ☐ Stay focused on the longer term benefits of weight gain/loss and the positive health benefits that it could have on your life, e.g. increased energy, less respiratory infections, etc.

Many people with CF have normal, positive eating habits and maintain a good BMI, however, given the ongoing emphasis to eat extra calories despite at times feeling fatigued, nauseous or just not hungry, it's not surprising that some people develop abnormal eating behaviours. This includes things like over-exercising, or skipping enzymes.

Abdominal Bloating:

This is very common for many people, including those in the non CF community. It does affect how people feel about their body image.

"I only wear certain clothes due to my bloated stomach and don't eat as much because I don't want everyone to notice my belly! It stands out so much more when you have thin arms and legs, too." (Female, 22)

"I often get asked if I'm pregnant and although I laugh it off, it does hurt." (Female, 24)

What causes it?

- Constipation, slow gut or diarrhoea
- Stress or anxiety
- Increased gas, swallowing air or a failure to expulse air
- Fluid retention
- Food intolerance
- Pre-menstrual
- Weakness of abdominal muscles and poor posture

Specific CF issues:

- Mismatching enzymes – experiment and/or speak with your dietitian
- Imbalance in weight distribution – lack of muscles on arms and legs can make the belly seem greater
- Distal Intestinal Obstruction Syndrome (DIOS) happens when mucus and food block the bowel, causing pain, bloating and cramping.

Coughing:

Many people have periods where they experience chronic cough. In a survey made in the UK, 81% reported being embarrassed by chronic cough.

"I get tired of the usual 'you should give up the fags' or 'you're not old enough to smoke' even when the person is joking." (Female, 22)

"Coughing does not stop me getting out because it's more important to live life than spend time being self-conscious." (Male, 26)

There are no simple answers other than finding a routine that helps. Some people find that they are more prone to coughing in the morning due to an accumulation of mucus throughout the night, so trying to do airway clearance in the morning and short episodes during the day could help with this.

Ab Bloating Quick Tips:

- ☐ Diet – regular meals, snacks and fluids throughout the day can reduce bloating and constipation. Avoid eating too quickly and swallowing lots of air
- ☐ Exercise – will help redistribute weight and improve muscle tone
- ☐ Don't lose weight (unless recommended by dietitian or doctor) as it may make things worse

Patient Tips:

"Make sure your back is straight because it will help reduce the bloated look somewhat". (Male, 23)

"Don't try and lose weight because if we lose weight we just end up being skinny with big bellies instead". (Female, 43)

Continence:

Urinary incontinence is very common amongst women with CF, with studies indicating as many as 68% of women having experienced it. Some women even have issues in childhood, or pre-puberty. Some men also report issues, however, it is not as common.

Stress incontinence is an involuntary loss of urine due to the pelvic floor muscles not coping with increased pressure on the abdomen, particularly at times like coughing, running, sneezing, laughing, jumping and heavy lifting.

"I didn't realise there were treatments to help, so I hadn't mentioned it until I was asked at clinic." (Female, 30)

"When I have to cough or sneeze it's really annoying. I deliberately clench or even cross my legs to stop this. It's really embarrassing, but the other outcome would be worse." (Female, 25)

Continence Quick Tips:

- ☐ Physio – cough in an upright position and suppress your cough until you're ready to clear sputum. Sip water and relax your breathing to help suppress cough
- ☐ The 'Knack" – contraction of the pelvic floor just before, and throughout activities that cause coughing
- ☐ Diet – constipation causes straining of the pelvic floor and potential incontinence. Seek dietary advice if this is an issue
- ☐ Pelvic floor exercises – identify the muscles that stop urine mid-stream and pull them up toward the diaphragm and hold for three seconds, preferably three times a day (seeking more detailed advice to do this properly is recommended)

REFERENCES:

- Continence Foundation of Australia http://www.continence.org.au/pages/get-help.html
- Didsbury & Thackray, 2010 cfbodyimage@gmail.com
- Financial Assistance http://www.continence.org.au/pages/financial-assistance.html
- Free Helpline 1800 330 066
- Simon, S., Duncan, C., Horky, S., Nick, T., Castro, M & Riekert, K, (2011). Body satisfaction, nutritional adherence and quality of life in youth with cystic fibrosis, Paediatric Pulmonology, 46:1085-1092.
- Stonestreet, J., Matson, A & Herd, K (2015). The prevalence of obesity at the adult cystic fibrosis centre, Brisbane. Adult Cystic Fibrosis Centre, the Prince Charles Hospital, Brisbane, Queensland

Ports and PEGs:

A port is a small device inserted under the skin to assist in frequent use of antibiotics, often suggested when someone has small veins or is requiring frequent intravenous (IV) medications. Generally discreet, causing a small bump under the skin.

A Percutaneous Endoscopic Gastrostomy (PEG) or gastrostomy tube is inserted into the stomach to assist in gaining weight by providing overnight feeds. After three months the tube may be changed to a 'button' which looks like a small valve and is quite discreet.

"I had a say in where my port went – I got the marker pen out and chose where it would be placed on my side." (Male, 24)

"Once I got the PEG the pressure to eat was gone so I could eat what I liked without constantly thinking of the fat content. I love it!." (Female, 26)

Scarring:

Most people with CF get scars, some wear them as badges of honour. However a UK study found that 68% of people felt that their scars affected their body image.

"They don't actually bother me at all. I'm actually quite proud of my transplant scar because it's the biggest (and best) thing that has happened to me." (Female, 24)

"I think part of disliking the scar is because it reminds me why I needed the port – because my health is in decline and I was needing more courses of IVs. Now I think of how much easier IVs are and the scar is a lot less intrusive and visible than I thought it would be." (Female, 28)

We all scar differently depending on age, race, genetics, general health, size, depth, location and type of injury.

Salt and Sweating:

People with CF have a much higher concentration of salt in their sweat which can sometimes form crystals on the skin (more so after exercise or in hot weather). Excess sweating is not known to be directly related to CF, however many people report excessive sweating in addition to salt loss which can impact body image.

"I met my husband in a hot nightclub and refused to kiss him for ages because I was so aware that I had been sweating and my lips tasted salty. Luckily it didn't put him off as we got married four years later." (Female, 31)

Excessive sweating can indicate an underlying medical condition such as infection or diabetes, so seek further medical advice.

Scarring Quick Tips:

- ☐ Moisturising – can speed up the healing process. No particular type is seen as preferable
- ☐ Silicone – silicone patches or gel can soften, flatten and smooth scars and relieve itching. Available over the counter or on prescription
- ☐ Heat – paraffin wax or heat application can be beneficial in scar reduction, however seek professional advice for correct application
- ☐ Camouflage – a number of products are available over the counter
- ☐ Plastic surgery – laser therapy and other procedures could be beneficial

Salt and Sweating Quick Tips:

- ☐ Extra deodorant and a change of clothes - have these on hand if exercising
- ☐ Test clothes – put a couple of drops of water on the hem of a piece of clothing to see if it goes really dark when wet, if so don't buy it
- ☐ Carry wet wipes – useful to carry in your bag
- ☐ Anhydrol Forte Deodorant or other prescription deodorant blocks the sweat glands and eventually turns them off. Used on small areas such as under arms, feet and hands. Discuss with your doctor
- ☐ Deodorant talcum powder – can reduce sweating

Sibling and Offspring Camp

The 2015 Sibling and Offspring Camp was held on the 8th and 9th of October and was attended by 20 children with a sibling or parent with cystic fibrosis (CF).

This annual event is designed to bring together young carers from within the CF community to enjoy a fun, adventure-filled two day camp. The camp is designed to initiate the development of important support networks between both children and Cystic Fibrosis WA (CFWA) staff, as well as allow time for respite and the opportunity to learn about CF and share experiences with others from this unique group. This year's camp was held at Bickley Recreation Camp and included a range of fun activities such as flying fox, canoeing, search and rescue, team building, vertical challenge and mountain bike riding. We also did some group activities where the children had the opportunity to ask questions and talk openly about their thoughts and experiences.

The Sibling and Offspring camp is designed for children aged 8 to 16 years and is held during the October school holidays each year. If you have a child who qualifies for the camp and has not received an invite in the past, please contact Gillian on **recreation@cysticfibrosiswa.org** or **08 9346 7333** to be added to the invite list for future events.

A big thank you to Commonwealth Bank for making this camp possible.

Keeping Mentally and Physically Healthy:

Michael Cahill

At 36, Michael Cahill, who lives with cystic fibrosis (CF), has achieved some amazing milestones and works really hard alongside his wife, Natalie, to make sure they have the best life they can with their daughter, Zoe.

RED: What do you do to keep mentally healthy?

My daughter, Zoe, and my wife, Natalie, keep me going. Having a full time job which I've always had since I was 16, motivates me. If I want to support my family and have a mortgage I have to keep my job. I'm a Business Development Manager at Signs Ahead and I've been there for a few months. Before that I worked at Signhere Signs as a manager for over ten years.

If I have a bad day I will call Nat and ask her to get a picnic basket ready and we will go for a picnic at Whiteman Park. I also allow myself to chill when I need to. If it's the weekend and I should be cleaning the house or whatever, but I need to chill, that's what I will do. I watch movies with Zoe or we play computer games and just wind down and forget about any rough times that might be happening.

We also have exchange students come to stay with us as company for Zoe. They stay for ten months of the year so I need to be mentally and physically healthy for that, too, as it's another child we are responsible for. Last year we had a lovely American girl named Molly and this year we have a lovely German girl named Paula.

Natalie and I have had our down times such as going through IVF. It took us three years to finally be able to have Zoe. It was a hard and depressing time but together Natalie and I have conquered a lot of ups and downs. We have been together since Nat was 17 and I was 18. We now have our second house together and have made it accommodating for when we need to just chill out. Natalie has her craft room and I have a "man cave" (which Zoe likes to take over) and that helps us have space when we need it.

Michael and daughter, Zoe, at the starting line of the HBF Run for a Reason

RED: What do you do to keep physically healthy?

Since 2014, I've been on the trial for the mixed Kalydeco® combination, Lumacaftor and Ivocaftor, which has improved my health dramatically. I feel it has had the most impact on me out of all the medications I have taken during my life. I've had no chest infections or hospitalisations since I've been taking Kalydeco®. I also cough a lot less which makes a big difference to me, too. Surprisingly, the results of my lung function in the clinic haven't yet showed a huge improvement, but I feel great. I can do so much more than I could before.

My health was steady before I took Kalydeco®. I could do a bit of running and bike riding but when I crashed and burned, I really crashed and burned. Whereas since I've been taking the Kalydeco®, I have found I can do so much more.

In 2014, I started going to the gym more often and then I decided to take up running.

My goal was to do the HBF run in May 2015, so before that I did the Aveley Park Run that our German student, Paula, got me into as she liked running too. I also did the "Great Strides" 4 km run in November 2014 with Zoe. We both trained for that each day after she finished school. Currently I do Aveley Park Runs which are 5 km runs most Saturdays with Zoe. In the last five months I have completed 12 park runs, 7 of them with Zoe by my side. The Park Runs are a world-wide thing where they give you a bar code and time your run. In 2013 before I started Kalydeco® and training for running, I could run about 2 km in 20 minutes, whereas now I can run 5 km in 28.55 minutes, which is my personal best. I am now aiming to be able to run 12 km.

RED: How do you stay on track with your treatment, work and family?

We have a good routine so we fit everything in, as Natalie works, too, and Zoe does dancing a few times a week plus her other after school activities, as well as Paula's after school activities. We are disciplined in getting stuff done and if someone in our family needs something we just do it and work out the logistics later.

I always take my required medications as all my meds, together with the Kalydeco® , is what keep my body going. Missing a dose sets me back and I don't have time for that. I always find time for my nebs and inhalers, usually at night and close to bedtime works well for me.

RED: We hear you have a big trip planned to the US at the end of this year. Tell us about that.

We decided in 2014, since my health was getting better, that December 2015 would be a good time for us to go to the US as there is less chance of me having issues while we are there. Plus Zoe doesn't have to miss any schooling. We are going to the east coast of the US: Orlando (Disney World and Universal Studios), Texas, Washington and finish in New York. We are going away for five and a half weeks in total and will fly to most of the places, except Texas, where we have hired a car and will be staying on a ranch for a week.

This trip has taken a lot of planning, working and saving, and getting my health in a good way so we can go. Natalie has done a lot of the planning. I was able to get insurance for the trip through Insure and Go® and my health is fully covered. They are the only insurance company that would cover me. I am aiming to mainly go to the local GP in the US if need to. I will also have one backpack full of my medication for the plane and some spares in my suitcase just as back-ups. I am going to get extra medication to keep at home, ask my local chemist to have some medications on hand and give my prescriptions to my dad so that in a worst case scenario, he can post them to me if needed.

Planning and preparing for this trip has been a huge motivation for me to keep on track with my treatment and look after my health.

I think what keeps me healthy, both physically and mentally, is having big goals with Natalie that we both work together to achieve. Our next thing to focus on when we get back from our trip will be to do some upgrades to our house and look at getting a new car – the bank loves us! But keeping financially stable and wise with our money keeps us working hard and allows us to enjoy our life together.

RED: THANKS MICHAEL FOR SHARING YOUR STORY WITH US!

Keeping Mentally and Physically Healthy:

Elliot and Ian Anderson

We know many families struggle with the diagnosis of cystic fibrosis (CF) and we are interested in sharing strategies and ways that you manage the many challenges along the way.

Elli and Ian Anderson have an active toddler who has CF. This is a little insight into how they face the day to day challenges.

RED: What do you do to keep mentally healthy?

When Oli was born premature and ill our world crumbled beneath us, we made the decision that whatever happened, however stressed, tired or grumpy we got, we would always stick together. We share the same goal – only wanting the best for Oli. We talk about everything openly and honestly and support each other 100%.

The trauma surrounding Oli's birth - CF diagnosis, surgery and the time in the Neonatal Intensive Care Unit - was so difficult to deal with. Without seeking help from a psychologist I wouldn't have been able to cope with my new life as a mum. It's so important to recognise when you need professional help and to access it without feeling embarrassed or like a failure.

RED: What do you do to keep physically fit?

Oli is a ball of energy! Most of our days are spent in our backyard chasing around our chooks, kicking the ball, going for walks, swimming or going to the park. We often play hide and seek or chasey through the house. Oli loves helping us bake so we like to try out new healthy recipes.

RED: How do you stay on track with managing treatments, appointments, work, family etc?

Our number one priority is keeping Oli healthy. This means that his physio and medications are routine parts of our day. In saying that, I have learnt that it's important to be flexible. If we are invited out at the last minute to breakfast we do physio a little later or if we forget a dose of medication we catch up. We tailor these things to suit our family, for example: we initially found clinic visits and hours of waiting in pharmacy awful and we began to dread appointments. This had an impact on our mental health and we knew we had to do something to make visits family friendly. We now drop off our prescription and plan to have breakfast or lunch in Subiaco a few days later so we can collect our medications without the stress.

RED: How do you deal with unexpected challenges?

Support from our extended family has been crucial in maintaining balance in our lives. We have a number of people who we can call for help at the drop of a hat. I find comfort in the fact I can phone the CF nurses if I have any concerns or questions about Oli.

RED: Tell us how you enjoy family time.

We love being at home, laughing and playing together. As long as the three of us are together, we are happy!

Ian, Oli and Elliot Anderson

RED: Anything further you wish to add?

Sure. We are parents of a child with a chronic illness but we are just like every other young couple trying to battle through life with a toddler! We aren't defined by the disease.

It has taken time to go from constantly thinking of CF to it just being a small part of our lives. Spending quality time together and not taking life too seriously gets us through the tough days.

RED: THANKS ELLIOT AND IAN FOR SHARING YOUR STORY WITH US!

Keeping Mentally and Physically Healthy:

Guy and Lisa Daniel

Guy and Lisa have shared part of their story about how they manage to stay active and positive as they face the challenges of life with a child with cystic fibrosis (CF).

Guy, Lisa, Taj and Ben Daniel.

RED: What do you do to keep mentally healthy?

Take time out together as a couple whenever we can. Whether we go for a coffee or have a date night, we try and ensure we continue to communicate openly and regularly.

As a family, we stay active and positive and try to have lots of fun whenever we can. We encourage Taj and Ben to remain active and participate in varied sports and activities, for example, gymnastics, basketball, Auskick football, hip hop dancing and swimming.

RED: What do you do to keep physically healthy?

Guy works in a physically demanding job which helps keep him fit. We have also set up a small home gym which we try to use as regularly as we can.

The boys and I walk to school as often as possible. We also have a trampoline on which both boys enjoy endless hours of fun.

Again, we encourage the participation in a healthy balance of sport and activities.

RED: How do you stay on track with managing treatments, appointments, work, family, etc?

We work very hard to adhere to a strict regime which includes physio before and after school and a nightly nebuliser. Most medications are taken at the start of the day which makes it easier to remember.

Guy is self-employed which provides some flexibility in relation to attending appointments and achieving a healthy work/life/family balance.

We also rely heavily on support from my mum and dad for three-monthly clinic and annual bronchoscopy/review appointments.

We have found that it is absolutely critical to diarise every appointment and to remain organised.

RED: How do you deal with unexpected challenges?

When challenges arise, we rely heavily on support from Grandma and Pop and again we find being organised in the beginning in varied aspects can give us a bit of a head start. It is important we remain in a position to react quickly if needed.

RED: Tell us how you enjoy family time.

We try and make the most of the 'good times' as you never really know what's around the corner. Therefore, when Taj is in a good place, we are out and about going to the park, catching up with family and friends, being active, playing football and going out for lunch.

RED: Anything further you wish to add?

We always work hard to remain positive and are forever hopeful that technology will provide significant improvements in the management of CF in the near future. Thus, providing a much better prognosis for Taj than if he were born when we were. The support we get from Princess Margaret Hospital and Cystic Fibrosis WA is amazing and makes a huge difference to us as parents for which obviously we are very grateful.

RED: THANKS GUY AND LISA FOR SHARING YOUR STORY WITH US!

Mental Health Support Services

Where to go for support and help

GP Mental Health Care Plan - Medicare rebates for counselling are available for up to ten individual and ten group allied mental health services per calendar year for people experiencing anxiety and/or depression.

Mental Health Emergency Response Line® – Rapid response to mental health emergencies, including advice for carers.
08 9224 8888

Parenting WA® – Information, support and referral services to parents, carers, grandparents and families with children up to 18 years.
08 6279 1200

Carers WA® – Support for carers. Carers can include parents, spouses and siblings of people with CF Free call from anywhere in WA.
1800 242 636

Sexual Assault Resource Centre (SARC)® – Free assistance and support to any male or female, aged 13 years and over, who has experienced unwanted sexual contact or behaviour. Counselling also available.
08 9340 1828
http://www.kemh.health.wa.gov.au/services/sarc/

Arbor® – Free outreach counselling service for those bereaved by suicide or sudden death.
08 9266 1029

Child Protection Unit® – Within Princess Margaret Rose Hospital. Ensures that children are protected whilst in hospital and on discharge. Covers child abuse, injury, neglect and wellbeing.
08 9340 8646

Ngala Family Resource Centre® – Early parenting services, support and guidance for families and young children.
08 9368 9368
http://www.ngala.com.au/

Youth Focus® – Working with young people aged 12-18 years who show signs of depression, self-harm and suicide. Also supports families.
08 9266 4333
http://youthfocus.com.au/

SANE® – Information and helpline for people with mental health issues.
1800 187 263
https://www.sane.org/

Beyond Blue® – Information on a wide variety of mental health problems for sufferers, carers and professionals.
1300 224 636
https://www.beyondblue.org.au/

Fremantle Multicultural Centre® – Crisis accommodation and settlement programs for refugees and migrants. It also operates a mental health referral program.
08 9336 8282

Anxiety Advice® - Anxiety Advice is a website offering advice to people with anxiety and or depression and to their families. Here you will find a wide variety of articles relating to depression, anxiety and other clinical disorders.
http://www.anxietyadvice.com.au/

OTHER SUPPORT SERVICES

Lifeline® - Telephone crisis support, suicide intervention and prevention, mental health support service
13 11 14
http://www.lifelinewa.org.au/

Crisis Care® (Family Helpline) – Problems within the family, including domestic violence, homelessness, child welfare and general arguments.
08 9223 1111 (metro) or 1800 199 008 (country)
http://www.health.wa.gov.au/

Kids Helpline® – Free telephone and online counselling service for young people between 5 and 25 years.
1800 551 800
http://www.kidshelp.com.au/

Men's Line® - Dedicated service for men with relationship and family concerns.
1300 789 978

Women's Domestic Violence Helpline® – Free telephone support and counselling for women experiencing family and domestic violence.
08 9223 1188
http://www.dcp.wa.gov.au/crisisandemergency/pages/domesticviolencehelplines.aspx

Men's Domestic Violence Helpline® – Telephone information, referral and counselling service for men to help them change their violent behaviour towards female partners.
08 9223 1199 (1800 000 599)
http://www.dcp.wa.gov.au/crisisandemergency/pages/domesticviolencehelplines.aspx

Rural Link® – Specialist after-hours telephone service for the rural communities of WA. Deals with depression, mental health issues, and suicide.
1800 720 101
http://www.mentalhealth.wa.gov.au/Homepage.aspx

The Samaritans® – Non-religious, non-judgemental care line, offering emotional support to the lonely, despairing and suicidal.
Samaritans Care Line – 08 9381 5555 (metro)
Samaritans Care Line – 1800 198 313 (country)

Samaritans Youth Line –
08 9388 2500
http://www.thesamaritans.org.au/

Alcohol & Drug Information Service® (ADIS) – Information, referral and counselling for substance users and family members.
08 9442 5000
http://www.dao.health.wa.gov.au/

RED Resources

Masters of Menu 2!

Submit and Win!

Our wonderful friends at Menu Magazine are taking on the challenge of producing a second Masters of Menu recipe book following the incredible success of the inaugural edition.

Due for publication mid 2016, the book will comprise recipes from leading restaurant and café chefs around Perth as did the first edition. However, the second edition will also feature the favourite cystic fibrosis recipes of our readers!

Those recipes selected by our panel of experts will have their recipe published and receive $100 in prizes each!

Submit your recipe by email to marketing@cysticfibrosiswa.org

SPILL®

A new sexual and reproductive health resource for adolescents

To demystify and improve communication and understanding about sexual and reproductive health for adolescents with cystic fibrosis (CF), a new online tool has been developed by Cystic Fibrosis Victoria and a range of experts in CF, sexual health and digital communications.

SPILL® (spill.org.au) has relevant, targeted and age-appropriate information in both text and video formats for teenagers with CF who are just learning about their sexual and reproductive health.

It is envisaged this will greatly assist health professionals' addressing this important aspect of growth, development and well-being with their CF patients.

Visit spill.org.au

Nutrition Program Coming Soon

Due to be launched early 2016, CFWA is currently working on a new set of community resources based on nutrition and food.

CFfood will include a set of four booklets aimed at nutrition in infancy, childhood, adolescence and adulthood. The resources will aim to educate the target audience about nutrition and the variety of concerns faced during each milestone. The resources will be endorsed by the Dietitians Group of Australia.

CFfood will also include a member recipe book and we would love a submission from you. This could be a main meal, snack, drink, dessert, etc. It may be a high calorie smoothie, a well-balanced dinner full of healthy fats, a breakfast that you can eat on the go - whatever you like!

We will also scatter useful recipes and tips throughout the rest of the resources, so if you have specific ideas for babies, toddlers, school lunches and other niche groups, please send those to us, too.

If you have calculated the calories, fat, protein and/or carbohydrates please include this with the recipe (per serve).

If you have time to also cook the recipe at home, please send in some photos to go along with the recipe. To ensure best quality, please send in photos with a minimum 2MB, taken with a digital camera if possible. If using a smart phone, it needs to be at least an iPhone 5 or 4S to ensure the picture quality is high enough. Please send a minimum of 3 photos.

CFfood cystic fibrosis nutrition program

CYSTIC FIBROSIS Western Australia

Name of Recipe: _____

Prep time: _____

Cooking time: _____

Number of serves: _____

Ingredients & Measurements: (use tsp, tbsp, gms, cups - Please dot point the ingredients)

_____

_____

_____

_____

_____

_____

Method (Step 1., Step 2., etc.)

_____

_____

_____

_____

_____

_____

_____

Nutritional information per serve
Calories:
Fat:
Protein:
Carbohydrate:

Thank you to Newman's Own Foundation® for making this project possible.

The recipe and photos should be emailed to Gillian on recreation@cysticfibrosiswa.org using the form that can be downloaded from www.cysticfibrosiswa.org/resources/cffood

CFfood cystic fibrosis nutrition program

NEWMAN'S OWN FOUNDATION

SUPPORTER SPOTLIGHT

Tim Cash – General Manager Exchange Tower

RED chats to Tim Cash about corporate support for charity and the association Exchange Tower has with CFWA.

RED: Welcome to RED, Tim. Can you tell us a little about the history of Exchange Tower?

In 1992, Exchange Plaza was completed and became home to the Australian Stock Exchange, hence the name. However, in 2015, the building was rebranded as Exchange Tower to reflect the contemporary vision of the building.

As one of the few premium office towers in the CBD we are very proud of the building and what it offers tenants and visitors.

RED: Exchange Tower is an impressive office building, it sets itself apart from many others in the CBD.

Yes, the highly functional building was designed to maximise the views of the Swan River. When Elizabeth Quay is completed, the building will have world class hotels, restaurants, shopping and other amenities on it's door step.

We have a host of first class amenities for everyone working or visiting the building - an in-house gym (Vault Fitness), concierge, 'state-of-the-art' end of trip change room and bike facilities, conference and theatre facilities, and a range of other personalised services.

RED: Exchange Tower has become a fantastic supporter of CFWA participating in the Golf Classic with a gold sponsorship and hosting the Vault 65 Roses Spinning Challenge. Can you tell readers about how Exchange Tower became involved in its charitable pursuits?

Our vision for Exchange Tower includes the building connecting with the community and we specifically want to connect with and support great charities.

Philanthropic Fridays is a title that we have given to one of our community programs which seeks to support charitable causes including CFWA and The Starlight Foundation. Most recently we held a "Spin Challenge" in conjunction with Vault Fitness in support of 65 Roses month fundraising. The tenants got right behind the initiative and we raised $4,000.

Exchange Tower also supported The George Jones Cystic Fibrosis Golf Classic which is an incredible event.

RED: When you aren't busy managing Exchange Tower, what do you like to do with your spare time?

I have a large family spread between Perth, Sydney and the UK and I love 'round ball' football – playing, coaching and watching.

I am also an enthusiastic global explorer and I have an ambitious plan of travelling through all 48 mainland states of America in a single trip. I have previously accomplished 26 states in one trip but 48 is the next challenge.

RED: Thanks for your time Tim. We appreciate you're very busy in and out of work!

'Most recently we held a "Spin Challenge" in conjunction with Vault Fitness in support of 65 Roses month fundraising. The tenants got right behind the initiative and we raised $4,000.'

Cross Country Ride for a Cure

Intrepid adventurer and CF mum, Beth Flatt, is gearing up for an epic coast to coast motorbike ride for a cure. RED recently caught up with Beth to chat about her journey and aspirations ahead of her fundraising challenge.

Hello Beth, thanks for your time. Can you tell our readers a little about what has inspired you to get involved with the trans-continent bike ride?

Since getting my motorcycle license earlier in the year and seeing the Ride for a Cure advertised, I knew that this was something I needed to pursue. I'm very passionate about motorcycle riding and obviously also cystic fibrosis research so to be able to combine the two seemed like a perfect combination.

RED: Who are the organisers and how many riders are expected to make the trek?

This ride is organised by Theresa Carlson who is the Ambassador for Cystic Fibrosis Australia, the main organisation looking into cure research. Theresa is hoping for about 50 riders to participate.

RED: Have you been riding motorbikes long and what do you plan on riding coast to coast?

My first ever encounter with a motorcycle was earlier in the year after obtaining my learners permit. I decided to go for a lesson and within three weeks I had my license and have ridden almost every day since! I have recently upgraded my little learner's bike for a Harley Davidson, which will take me from Perth to Victoria, and back for the ride.

RED: Do you have a fundraising target and how can supporters assist?

I have organized a CF Charity ride from Byford to Dwellingup on the 10th of October to help towards the entrance fee into the Ride for a Cure, which will go to Cystic Fibrosis Australia. Any other funds that I can raise will be going to CFWA. I am currently at over one thousand dollars just from donations and hope to get that up another couple of thousand after the October ride.

RED: THANKS FOR TAKING ON THIS INCREDIBLE CHALLENGE AND CHATTING WITH US TODAY BETH. WE LOOK FORWARD TO REPORTING ON YOUR ADVENTURES IN A FUTURE EDITION OF RED.

2016 Parents' Retreat

Save the date for the 2016 Parents' Retreat!

To be held at Hillarys Resort Harbour in Hillarys from the 11th to 13th March. Keep any eye out for more information about the event early next year.

For more information contact Gillian on recreation@cysticfibrosiswa.org or 08 9346 7333.

Farewell Denise Cork

It is with great sadness that we say goodbye to one of our Home Care Workers.

Denise started with Cystic Fibrosis WA (CFWA) in May 1993 servicing families in the southern suburbs and has recently celebrated her 22nd anniversary as a Home Care Worker. Denise is leaving us to spend more time with her own family. Her compassion, generosity and kindness will be greatly missed by everyone she has met over the years.

Denise would like to say thank you to her CF families who have given her so much joy. She is truly grateful for everything she has learnt from her families and will cherish the memories.

We wish her much love and all the best for her future journey.

Fundraising News

Thank you for all the hard work, hours given and tireless support from our exceptional fundraisers! Once again there has been an amazing show of support for CFWA.

The money raised is making a real difference, your ongoing support means a lot to us! Thanks so much!

We would like to express our gratitude to the small businesses and community groups who have made donations to help improve the quality of life of people living with CF! Thank you to **Cambrai Craft Group** for donating $200. The **Eaton Coffee Club** for your donation of $100. Thanks also to **Gregs Discount Chemist** for your donation of $100 and **Amcal, Inglewood** for donating $100. Thank you for your support!

COLLECTION TINS ADD UP!

We would also like to say thank you to the community fundraisers, businesses, clubs, individuals and community groups for taking the time to place collection tins. Every dollar really does make a difference and it can be surprising how these can add up.

Thank you to **Total Tools** in Bunbury for raising $27.00; **Bernard Stokes** and the **New Beaut Coffee Ute** for raising, $84.75. **Ron York and the team** from the **Men's Shed** collected $18.80; while **Harvey Bowling Club** collected, $47.50.

The **South West Women's Health Support Centre** collected $16.00 and the team from **Classique for Hair and Beauty** raised $17.00.

LJ Hooker raised $94.30 from a collection tin placed on their counter. Thank you also to the **Xpresso Code** for bringing in the amount of $123.45 and **The Good Guys at Malaga** for raising $169.

Jewel-Mend Jewellers contributed $263.20 through their money tin collection program.

Thank you! We are so very grateful for your ongoing support.

RUNNING FOR CF

We are continually amazed at the generosity of so many people who help us each and every day in our efforts to improve the lives of people living with CF. After months of training and preparation and training we had a faithful team of resilient runners who took to the streets. Thank you for your time and effort, hours of training and running, for the voice you have given to our cause, for your sweat, calories and miles. And of course, thank you for the money you have raised!

Thanks to **Kim Metcalf** who ran the Swan River Run on Sunday 26th July, having run very little previously. Amazingly, Kim committed himself to the 14 km run. Not only did he complete the 14 km run, but he raised an incredible $2,235.75!

Kim Metcalf on the 14 km Run with daughter, Elisabeth, (CF) and son, Anthony

"I went from someone who couldn't run 2 km ten weeks ago to someone who completed a solid 14 km in just over 90 minutes. Even though I was beaten by a guy running in army fatigues carrying his full backpack, and a girl carrying the Westpac Rescue Helicopter, I was satisfied with getting to the finish line!"

Many thanks to the team Swan River Runners who raised and amazing $4,294.64 and to the City to Surf runners for raising, $4,523.05! A brilliant effort from all involved.

And here are the individual results – thanks so much!

Kim Metcalf $2,235.75
Helen Addison $1,118.24
Sarah Houston $769.65
Nicole Spirkovski $126.00
Kelly and Abbey Barker $1,653.25
Karen Cooper $682.50
Mel Gahan Spreckley $670
Emma Walter $549.75
Perry Cunningham $415.80
Annie Tomley $260.00
Amber Goward-Bell $213.75
Fiona Mazzei $78.00

FUNDRAISING AT SCHOOL

Once again the school communities have been making an impact with free dress days, crazy hair days and gold coin fundraisers.

Thanks so much to all the teachers, students and parents for participating in helping to raise funds for CF!

Thank you to **Samson Primary School** for holding a free dress day and raising $312.00 **Kearnan College** for raising $258.05; and thanks also to **Wyalkatchem District High School** for raising $74.75

OUR FUNDRAISERS DO IT AGAIN!

We are so grateful to every faithful community fundraiser for making their presence known in their local communities. Whether it's cooking sausage sizzles, holding bake sales or selling raffle tickets, thank you for your commitment, your time and your labour of love!

Thanks to **Frances Stone** for holding a special champagne event with poetry, art and dancing, raising $550.00.

Katrina East and the **Big W team**, pooled their efforts together and raised a total of $450.00 Thanks so much!

Proving that age isn't holding them back, the residents from the **Baptist Care Sunshine Park Retirement Home** raised $146.50 by holding a crazy hair day!

Sally Walsh and the team from ANZ raised $50.00 by holding a free dress day and **Tom Leadbeatter**, along with the team from **NHPW Wrestling**, raised $350.00 at their annual ladies day.

Katrina East and the Big W team

A great big thank you also to the team from **The Good Guys Malaga** for collecting $2,219.19 through an instore token fundraiser.

Thanks to **Anyr Atak** for raising $144.75 by recycling clothing.

Westpac held a free dress day raising $75.50 while **Oliver Harding** sold his special brand of delicious home-made oats raising $926.00.

Holly Edwards-Smith has been busy fundraising for CF with her grand total efforts for the year reaching $2,461.91.

And **Ciara Taylor and the Red Run For CF** final tally reached an incredible $10,000! Ciara has a family friend living with cystic fibrosis so she is extremely passionate about raising funds to support research into finding a cure. Thanks Ciara and well done!

Hunter Jackson and his sister, Ella, after his 65 km run

Thank you also to **Caitlin Jones** for raising the amount of $1,500 by holding a bikini car wash and to **Lynda Carson** for raising $111.80 through community fundraising in July.

Sue Williams and the families from the South West area combined their efforts and teamed up for the 65 Roses Challenge, raising a grand total of $1,426.30. Thank you all!

65 KMs FOR 65 ROSES

If you like inspirational stories you are sure to love this one. Read inspirational story of seventeen-year old **Hunter Jackson** who took on the gruelling challenge of running 65 kilometers for 65 Roses – an endurance run for his sister to raise funds for cystic fibrosis.

THE RED TIE DINNER DANCE

On Saturday 29th August the very first Red Tie Dinner Dance went off with a bang at the Fremantle Sailing Club!

With the stunning sunset over the Indian Ocean providing the backdrop for the inaugural event, the evening was kicked off with a champagne reception followed by a sumptuous three course meal that was prepared by some of Perth's finest chefs. With plenty of mystery prizes, quirky photo opportunities and raffle prizes on offer, the elegant evening was not without a unique note of fun. Then to cap it all off, Tod Jonson's Peace, Love And All That Stuff stepped up the pace and created an irresistible draw, making it very difficult to say no to the dance floor.

Tickets for the Red Tie Dinner Dance sold out early and it is expected tickets will sell out quickly again when the event comes around in 2016. The grand total raised from the evening was $17,083.66. An excellent result for an inaugural event!

Thank you to the **Fremantle Sailing Club** and the **Fremantle Sailing Club Organising Committee** for your time, commitment and hard work to host the Red Tie Dinner Dance. We can't wait for the event to come around again next year!

THANKS ALSO GOES TO…

We would also like to express our gratitude to the organisations and who have made contributions CFWA through their Community Contribution and Employee Achievement Programs. With this is mind, thank you to **Myer** for your contribution of $10,110.45 and **Woodside Energy** for $2,500. We appreciate your support and can't thank you enough!

Have we omitted your fundraising efforts from RED? From time to time, we receive 'unknown' donations without any information. Please contact our fundraising team on 08 9346 7333 to make us aware of your contribution.

A fantastic evening was had at the inaugural Red Tie Dinner Dance.

US Generosity Extends Helping Hand to CFWA

With special thanks to Alcoa and their global network, Cystic Fibrosis WA is now eligible to receive grant funding from donors in the United States via the Silicon Valley Community Fund (SVCF).

Appearing on SVCF's own site as well as its partner site, YourCause, allows matching gift opportunities from US donors such as Alcoa or Alcoa employees to choose CFWA as their charity of choice. In 2014, charities in 56 countries received USD$18million from SVCF making it the largest community fund in the Unites States with global philanthropic participation.

"The US is known for its giving culture and philanthropy; to benefit from that kindness halfway around the globe here in Perth is incredible", said Nigel Barker CEO. "With the assistance of SVCF and other like organisations, Cystic Fibrosis WA will continue to deliver vital services to people living with the condition whilst the search for a cure continues".

CF Diary

Please note these dates were correct at the time of printing but are subject to change

NOVEMBER

7 › Convicts for a Cause
20 › CFWA Christmas Party & Awards Evening

DECEMBER

18 › CFWA office closes

JANUARY

4 › CFWA office reopens

MARCH

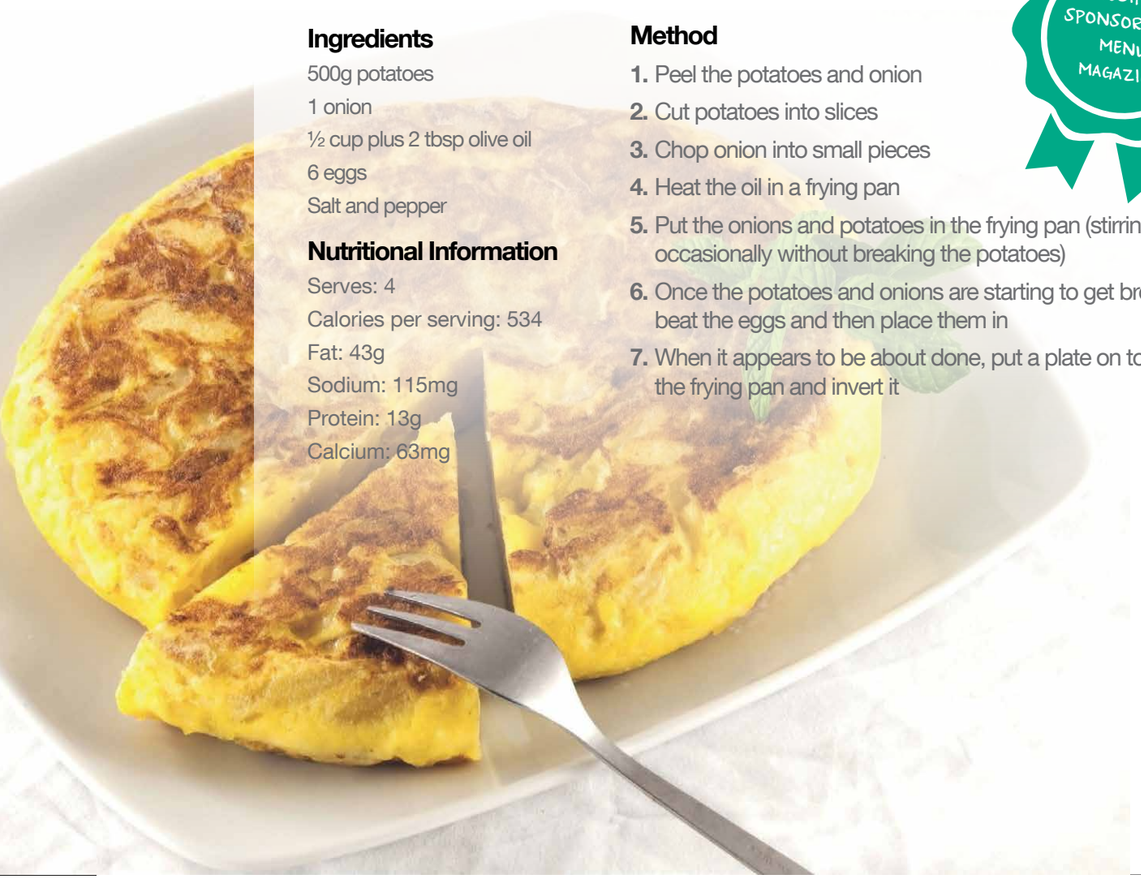
11-13 › Parents' Retreat

Spanish Omelette

A quick, nutritious meal ideal for breakfast, lunch or dinner

Recipe sourced from CFchef® www.chef4cf.com/recipes/lunch.html

RECIPES SPONSORED BY MENU MAGAZINE



Ingredients

500g potatoes
1 onion
½ cup plus 2 tbsp olive oil
6 eggs
Salt and pepper

Nutritional Information

Serves: 4
Calories per serving: 534
Fat: 43g
Sodium: 115mg
Protein: 13g
Calcium: 63mg

Method

1. Peel the potatoes and onion
2. Cut potatoes into slices
3. Chop onion into small pieces
4. Heat the oil in a frying pan
5. Put the onions and potatoes in the frying pan (stirring occasionally without breaking the potatoes)
6. Once the potatoes and onions are starting to get brown, beat the eggs and then place them in
7. When it appears to be about done, put a plate on top of the frying pan and invert it

Questions About Living With CF

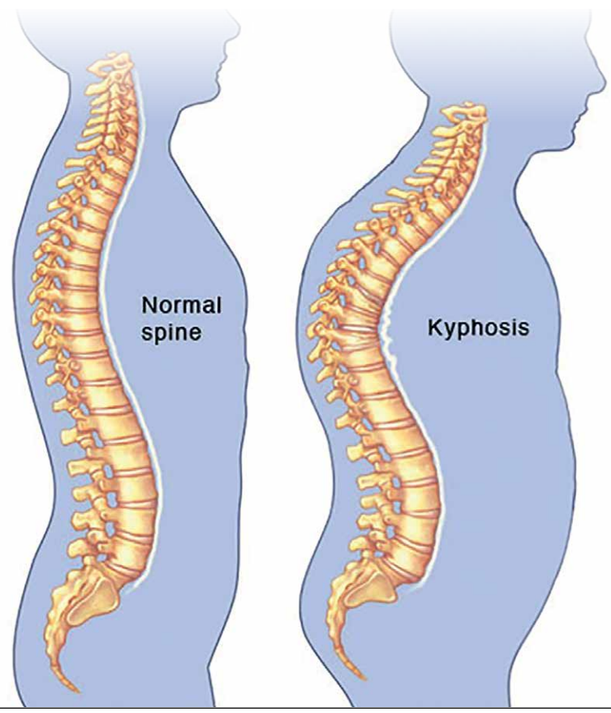
'I have noticed when I look in the mirror lately that my shoulders and back look rounded and I sometimes get pain in my neck and back which gets me down. Is there anything I can do to manage this and stop it from getting worse?'

Changes to posture are quite common in cystic fibrosis (CF) and are very often associated with pain and a decrease in self-confidence. It can also make it harder to do your airway clearance and exercise which may have a negative impact on your health and the way you feel about yourself.

Ideal posture allows the muscles and joints to be in a position that involves the least amount of effort and overload. Postural changes occur when the muscles and joints adapt to the abnormal position of your body, placing extra stress on them and often leading to pain. In CF, an increase in the forward curvature of the upper spine (thoracic kyphosis) can occur as a result of the posture adopted for breathing and coughing.

Being aware of your posture and incorporating stretches into your everyday routine is important to prevent postural changes from occurring. If you are already experiencing changes to your posture and joint or muscle pain, it is not too late to start exercises to address these issues.

Improving your posture can have a positive impact on body image and self-esteem and also improve your pain and lung disease. Talk to your physiotherapist in clinic as they can suggest stretches and positions for airway clearance and nebulisation to help address any posture and pain issues you may be having.
They can also assess the need for extra interventions such as hands-on therapy and other pain management techniques.



USEFUL RESOURCES:

- www.cysticfibrosis.org.uk/media/82155/EB_CF_and_Body_Image_Jan_11.pdf
- http://www.rbht.nhs.uk/patients/condition/cystic-fibrosis/cf-team/posture-issues-in-cf/
- www.thoracic.org.au/imagesdb/wysiwyg/physiotherapyforcysticfibrosisinaustralia_1.pdf

CONVICTS FOR A CAUSE 2015

BREAK OUT & MAKE A DIFFERENCE

Experience a night of charity, fun and mischief in the historic Fremantle Prison.

On Saturday November 7, dozens of people will be put behind bars for an evening of fun, suspense and entertainment. In order to be released, they must raise their bounty!

Convicts for a Cause is an annual cocktail party brought to you by Diabetes Research WA, Cystic Fibrosis WA and the Rotary Clubs of Perth & Mt Lawley.

Now in its seventh year, we are aiming to raise $120,000 which will make a huge difference in the lives of many sick children.

The night will consist of around 500 attendees dressed as their favourite convicts – some are being locked up, and others will just be there to join in the fun!

Hosted by 6PR's Steve Mills and interactive entertainment provided by the internationally acclaimed Ellandar Productions, the night will be fast paced with some unexpected twists.

Register as a guest or fundraising convict at: www.convictsforacause.org.au

Thank you for your support and we look forward to seeing you on the night!

When: Saturday, Nov 7 | *Where:* Fremantle Prison | *Time:* 7-11 pm

CYSTIC FIBROSIS Western Australia

Diabetes Research Western Australia

Rotary Club of Mt Lawley

Rotary of Perth