There is no health without mental health

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Outline

• Why is mental health important?

• Common psychosocial issues at different developmental stages

• Available support through your CF clinic and Medicare

• CFA’s mental health roadshow
Two types of health:

- Both mental and physical health are closely linked and influence one another.

- This is backed by the World Health Organization (WHO) that defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease.”
Mental health is Australians' most common ailment, GPs report

Half of GPs surveyed for new report say patients’ psychological problems the issue causing them most concern for future

▲ Psychological ailments are the most common cause for a patient visit to a GP, according to the latest Health of the Nation report. Photograph: Niall Carson/PA

Australians are seeing their doctor to discuss mental health ailments more than any other issue, according to a new report by the Royal Australian College of General Practitioners.
Why?

• More common or more acceptable/treatable?
• Working longer hours
• Weaker community ties and supports
• Cost of living, material pressures
• Social media – set high expectations for ourselves
Impact of Cystic Fibrosis

CF

- Health
- Family
- Mood
- Activity
- Sleep
- Eating
- Pain
- Independence
- Fitness
- Social Life
- School
Barriers to seeking help

- Embarrassment – will people judge or understand?
- Stereotypes in the media
- Stigma
- Labels
- Access
Diagnosis and Infancy
Diagnosis and infancy

• Diagnosis at NBS is the first period of adjustment:
  • Shock, loss and grief
  • Increased risk of depressive symptoms in caregivers
  • Families with the most difficulty at diagnosis continue to experience the highest levels of distress – need for early intervention

• Research suggests the following impact on relationships:
  • Mothers have concerns about how caretaking demands affect their marital relationship, sibling well-being, and family functioning
  • Increased tensions with partner
  • Mealtime enzymes and calorie demands – medicalise the family bonding time by reducing a parent’s ability to just be present/engaged
  • Even before the child becomes symptomatic families living with CF may look and interact differently to those without – waiting for the impact of CF to begin
A Parent’s Perspective of Adjustment

“Being told that your child has cystic fibrosis is never easy. There are so many adjustments that need to be made to your life as you begin to wrap your head around a diagnosis like this. I remember… feeling like someone pushed me off a plane in some foreign country, like Japan, without a guide book or a translation dictionary. I was standing still watching everything go on around me and I understood only a small fraction of what it all meant… over time, I adjusted… You learn the language of the land and the landscape, you accept the hours of treatments, you learn strategies for getting an 8 month old to take a nebuliser treatment or a 15-month old to swallow pills. You create a new normal, and the “Japanese” that sounded like gobblety-gook, starts to be a part of your vocabulary”.
Preschool Years
Preschool Years

• Children are beginning to have the language skills to process and make sense of CF:
  • Can attribute CF to biological factors such as ‘being born with it’ rather than ‘punished’ (Harbord, et al. 1987)

• Developmentally more likely to try to exert control over their environment at this age:
  • Behavioural problems, refusal to do medical treatment, avoidance of needles, etc.
  • Increased opportunity for parent-child conflict
“Normal” Development vs CF

• Anxiety regarding what is ‘normal’ for children, particularly for first time parents – importance of first mothers’ groups

• CF can exacerbate normal behavioural concerns in children aged 0-6yrs (Sheehan, 2002)
  • ~10% moderate/severe sleep problems
  • ~20% significant problems with eating behaviours (spits out, tantrums, negotiations, refusal)
  • ~6% externalising behaviours interfering with daily functioning (aggression, defiance, attention problems)
  • ~6% withdrawn, depressive, anxious, emotionally reactive
Eating/Feeding Issues

- Research has demonstrated a relationship between parental anxiety and fussiness/food refusal – difficult not to be focused on nutrition when a child has CF!
- Common issues:
  - Prolonged meal times
  - Food refusal
  - Difficulty swallowing enzymes
- Mealtime challenges can persist in teenage years if not addressed
- Use of behavioural treatments for feeding issues eg routines, time limits, rewards
Primary School Years
Transition to Primary School

• Movement towards encouragement of self-management
  • Parental lack of control when at school = anxiety!!!!!

• “Secondary diagnostic period” for children when starting Prep:
  • Comparison to their peers - other children don’t have CF
  • Highlight differences (coughing, enzymes, physio, missing school) when wanting to fit in
  • Coping with negative peer reactions (overprotection, teasing)
  • Need for a new understanding of what CF is that is developmentally appropriate with new language abilities
Primary School

• Children start to integrate CF understanding into who they are (improved cognitive abilities)

• Discussion about how to explain CF to other children:
  
  • Most children in lower grades of primary school seek others’ reactions when trying to decide how to react to new news/events

  • If something is ‘played down’, then the child reads from others’ reactions that this is not something to worry about or focus on

  • It is important to teach children and teachers a way to answer curious questions without placing a large emphasis on CF being a ‘bad’ thing
Child Opposition to Treatment

• Parental presence improves adherence, **but**…
• CF treatments increase opportunity for conflict
• The stress of daily treatments may make it difficult to implement limits and boundaries to improve child cooperation
• Strategies that involve the whole family can improve children's adherence to nutritional and physiotherapy treatments eg family routines around exercise and mealtimes
Phobias and Procedural Anxiety

• Very common in children with chronic illness
• Usually in context of a traumatic event involving lack of control

• Psychological techniques to reduce anxiety:
  • Psychoeducation eg how anxiety affects the body
  • Breathing and relaxation
  • Cognitive challenging eg replacing negative anticipatory thoughts with more positive ones
  • Imagery
  • Gradual exposure
  • Coping plan - distraction, increasing control, rewards
  • Educational play therapy involvement, if there is access
Adolescence
Transition to High School

• Important milestone and opportunity for “re-invention”
  • The child with CF can choose whether or not peers are informed of their disease
    • Disclosure is linked with improved psychosocial adjustment, and greater understanding of atypical behaviours = decreased rejection (Kerry’s example)

• Gradual movement towards independence and autonomy versus a possible worsening of symptoms with age
Feelings of Difference and Isolation

- Children with a chronic illness often feel isolated, different and that their peers don't 'get it'
  - Lack of control over life compared to peers
  - Increased parental involvement given illness
  - Medical regimen highlights differences
  - Social experiences impacted on (treatment burden, illness, admissions, etc)
  - Infection control = isolated from CF peer group
Adherence Issues

- Adherence issues in adolescence are common and difficult to address:
  - Overload of treatments – please communicate this with the MDT
  - Barriers to treatment vast- eg time, energy, prioritising school or social experiences, not seeing benefit of treatment, routine is important
  - Linking goals to treatment plan
  - Increase control/choice – brainstorm possible solutions
  - Psychological techniques can be helpful – discuss with your psychosocial team
Body Image in Media vs CF
Mental Health

• Increased risk of developing mental health problems during adolescence (linked to poorer adherence):
  • Adjustment issues
  • Depression
  • Anxiety
  • Needle phobia/procedural anxiety
  • Eating disturbances
  • Anger
  • Sleep disruption
• **Online services**: BRAVE program, Mood Gym, Headspace, Smiling Mind, Connecting up Adolescents
Other Medical ‘Milestones’ to Consider

• Hospitalisation
  • Increased isolation from peers, missed school, losing time academically

• CF-related diabetes – “another diagnosis!”
  • Affects 10-15% of children with CF
  • Increased treatment burden
  • Second adjustment period
    • Powerlessness and psychological distress common

• CF-related pain
  • 59% of children report 1 episode of pain in the last month
  • Impacts quality of life, increases anxiety and sadness
Transition to Adulthood

• Adolescents need support throughout this transition to ensure that they are capable of self-managing their health and treatment needs (Evelyn will address this later in the program)

• Parents report high levels of anxiety regarding transition to adult services
  • Fear regarding reduced involvement in their child’s care
  • Children generally more ready than adults (particularly if well)

• Fear of what adult hospitals will bring
• Fear that ‘getting older’ = ‘getting sicker’
• Sense of grief/loss associated with moving on
Adulthood
Adulthood

• Key issues:
  • Mental health (higher rates of depression and anxiety)
  • Adjustment to declining health, QOL
    → impact on work/income, family, social
  • Transplant
  • Financial concerns
  • Relationships
  • Family planning and fertility
  • Parenting
  • Advanced care planning
## Common Psychosocial Issues

<table>
<thead>
<tr>
<th>Psychological</th>
<th>Social</th>
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<tr>
<td>• Adjustment and coping</td>
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<td>• Mood/depressive symptoms</td>
<td>• Financial stress</td>
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<td>• Anxiety symptoms</td>
<td>• Parental relationship</td>
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<td>• Adherence</td>
<td>• Substance issues</td>
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<td>• Procedural anxiety/needle phobia</td>
<td>• Educational/employment</td>
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<td>• Sleep</td>
<td>• Child protection- medical neglect</td>
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<td>• Meal time</td>
<td>• Family violence</td>
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<td>• Medical trauma</td>
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<td>• Learning difficulties</td>
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<td>• Parent-child interactions/family relationships</td>
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Available support through your CF clinic

- Monash Medical Centre – psychologist Dr Hawran Baldey (new position, 10 hours/week, children, adolescents and adults), social worker is Naomi Erlich

- The Alfred – Dr Anthony Talbot (9 days/fortnight) and Nina Menezes (full time)

- RCH – Dr Jess Mifsud (4 days/week) and Romany Aitken-Wong (2.5
# Role of the Psychosocial Team

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<thead>
<tr>
<th>Psychologist</th>
<th>Social Worker</th>
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<tr>
<td>• Support through key transitions - diagnosis, transition to school/adult care</td>
<td>• Practical and emotional support for patients, families and carers</td>
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<td>• Psychoeducation</td>
<td>• Identification of psychosocial issues</td>
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<td>• Assessment and intervention for a range of emotional, behavioural and psychological issues</td>
<td>• Advocacy and referral to key support services</td>
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<td>• Lung transplant assessment and support</td>
<td>• Emotional support to patients with adjustment to declining health status</td>
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<td>• Consultation to MDT</td>
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<td>• Consultation to community-school, paediatricians, psychologists</td>
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<td>• Annual reviews</td>
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Funding for private psychology

• Mental Health Plan from your GP – access to Medicare rebate to cover a portion of the fee

• Telehealth for rural and remote patients

• APS website to search for a psychologist in your area

www.psychology.org.au/Find-a-Psychologist
The International Depression Epidemiological Study (TIDES)

• Evaluated the prevalence of anxiety and depression in caregivers of children and adolescents with CF who were recruited from 154 CF Centres across nine European countries and the US (Quittner et al., 2014)

• Elevated symptoms of depression were found in 37% of mothers and 31% of fathers, while elevated levels of anxiety were found in 48% of mothers and 36% of fathers
TIDES

• The same study used standardised measures of depression and anxiety in adolescents aged 12 years and over and adults with CF.
• Elevated symptoms of depression were found in 10% of adolescents and 19% of adults, while elevated symptoms of anxiety were found in 22% of adolescents and 32% of adults with CF. Symptoms of common psychological distress are therefore highly prevalent in parents, as well as adolescents and adults with CF.
• In adults with CF, depression and anxiety are associated with worse self-management, pulmonary function, quality of life, increased hospitalisations and greater healthcare costs.
CFA’s Mental Health Roadshow

- Supported by the CF Foundation (USA) and LJ Hooker Foundation
- Partner, parent, siblings and carer event on Saturday 10 November at the CFCC offices from 9 to 11am conducted by Dr Alexandra Quittner and Dr Anna Georgiopolous
- Information, strategies and advice to encourage and support better mental health
- Register now to attend!