Paediatric Depression : a side effect of parental chronic illness and pain

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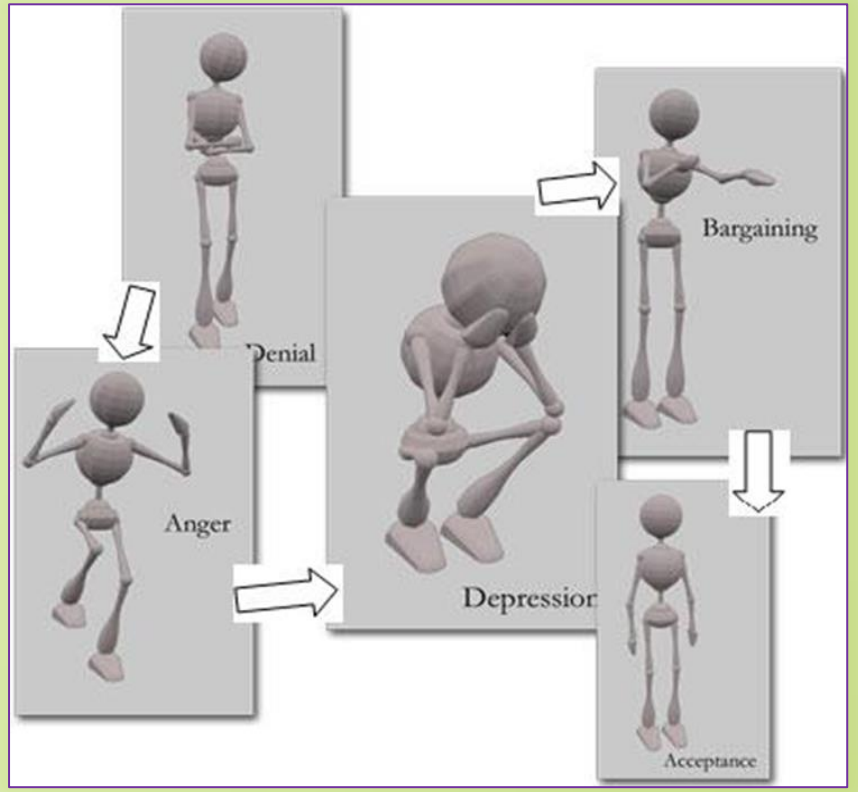
Introduction

- Chronic medical conditions or illness can be defined as a disease process lasting 3 months or more which may affect more than one organ
- Worldwide, it is believed that the prevalence of parents affected with chronic disease may be as low as 4% or as high as 12% Worsham et al 1997, Barkmann et al 2007
- So a number of families are having to cope with multiple distressing situations due to the impact of impaired parent function and illness
- I propose to review the specific impact on mental health by considering
  - the role of the disease process
  - the role of an ill parent's emotional state
  - child specific factors
- Finally, I will review a specific mental health condition - depression

Impact of Disease Diagnosis on Coping

- A diagnosis of a chronic disease will often precipitate a grief reaction
- This is however a perfectly normal aspect of the coping pathway
- **It does not signal a potential negative mental health outcome for the affected parent and family**

Need to consider other biological, psychological and social factors



Impact of Bio Psycho Social Factors

- Biological factors – disease process
  - Type of illness
  - Severity and course of illness
  - Functional impairment
- Emotional state of the affected parent

Child Specific Factors

- Age and gender of the child
- Role of the child as a young carer

Disease Process : Type of Illness

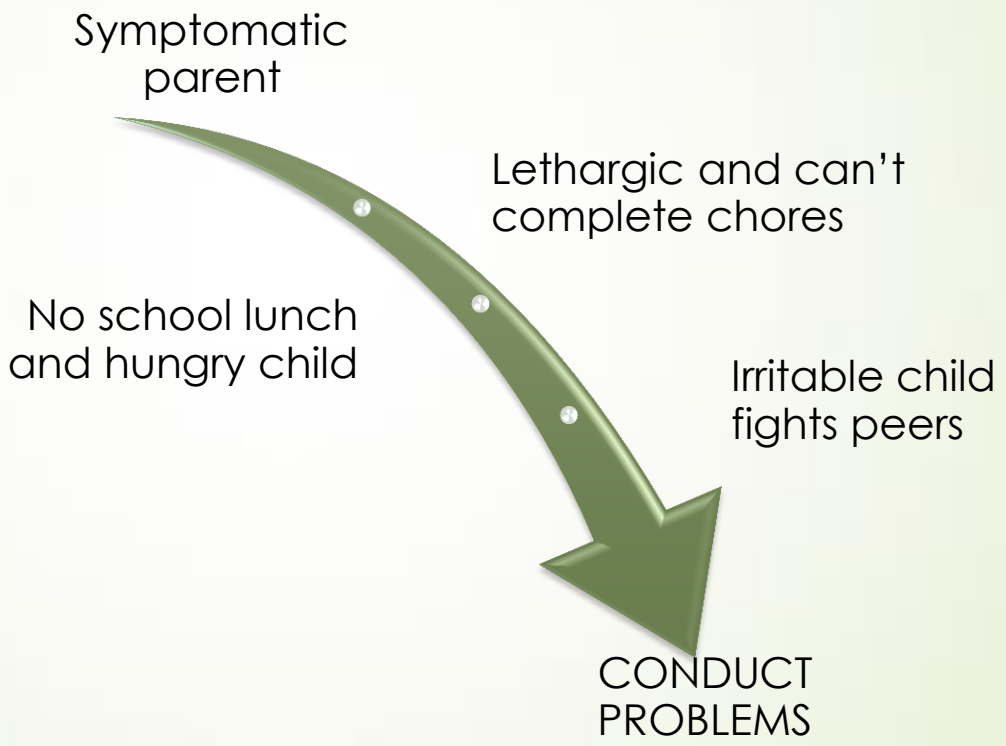
Disease Process : Severity & Course of Illness

- Frequent hospitalisation
- Prolonged hospitalisation
- Witnessed parental suffering
- Terminal condition

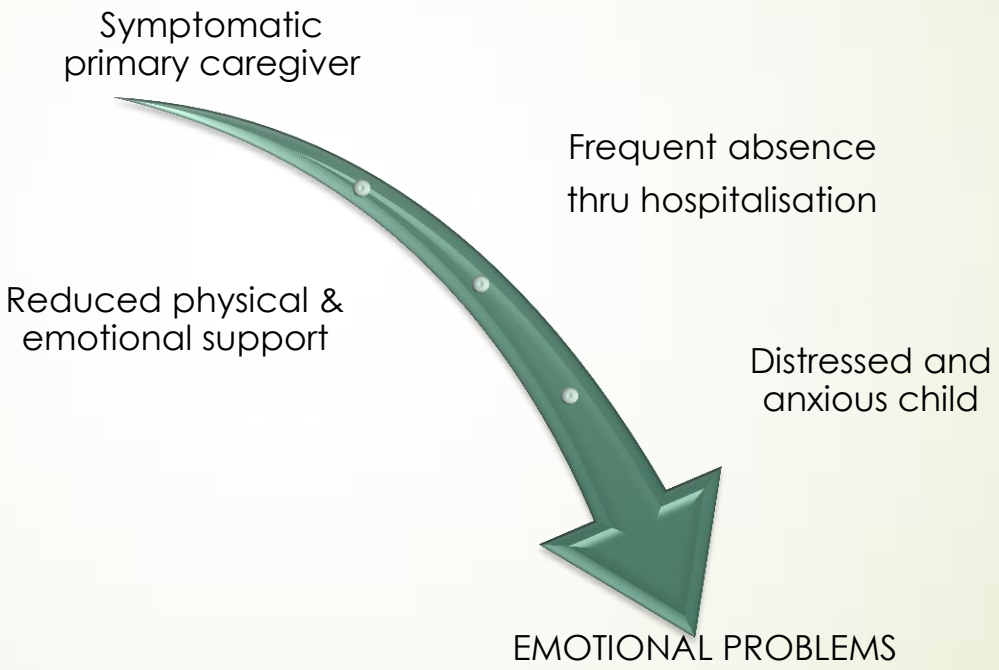
Disease Process : Functional Impairment

- The increased ‘everyday grind’ tends to take a toll on children
- Korneluk and Lee in their 1998 review noted that the perception of stressfulness rather than objective illness affected coping
- Dufour et al (2006) noting the impact on children of parents with Parkinson disease and stroke shared similar findings re: daily hassles
- This may be due to reduced parenting by the adult and consequences
- Reduced quality of life through straitened economic circumstances

Example 1


Symptomatic parent
Lethargic and can't complete chores
No school lunch and hungry child
Irritable child fights peers
CONDUCT PROBLEMS

Example 2


Symptomatic primary caregiver
Frequent absence thru hospitalisation
Reduced physical & emotional support
Distressed and anxious child
EMOTIONAL PROBLEMS

Impact of Bio Psycho Social Factors

- Disease process
  - Type of illness
  - Severity and course of illness
  - Functional impairment
- Emotional state of the affected parent

Child Specific Factors

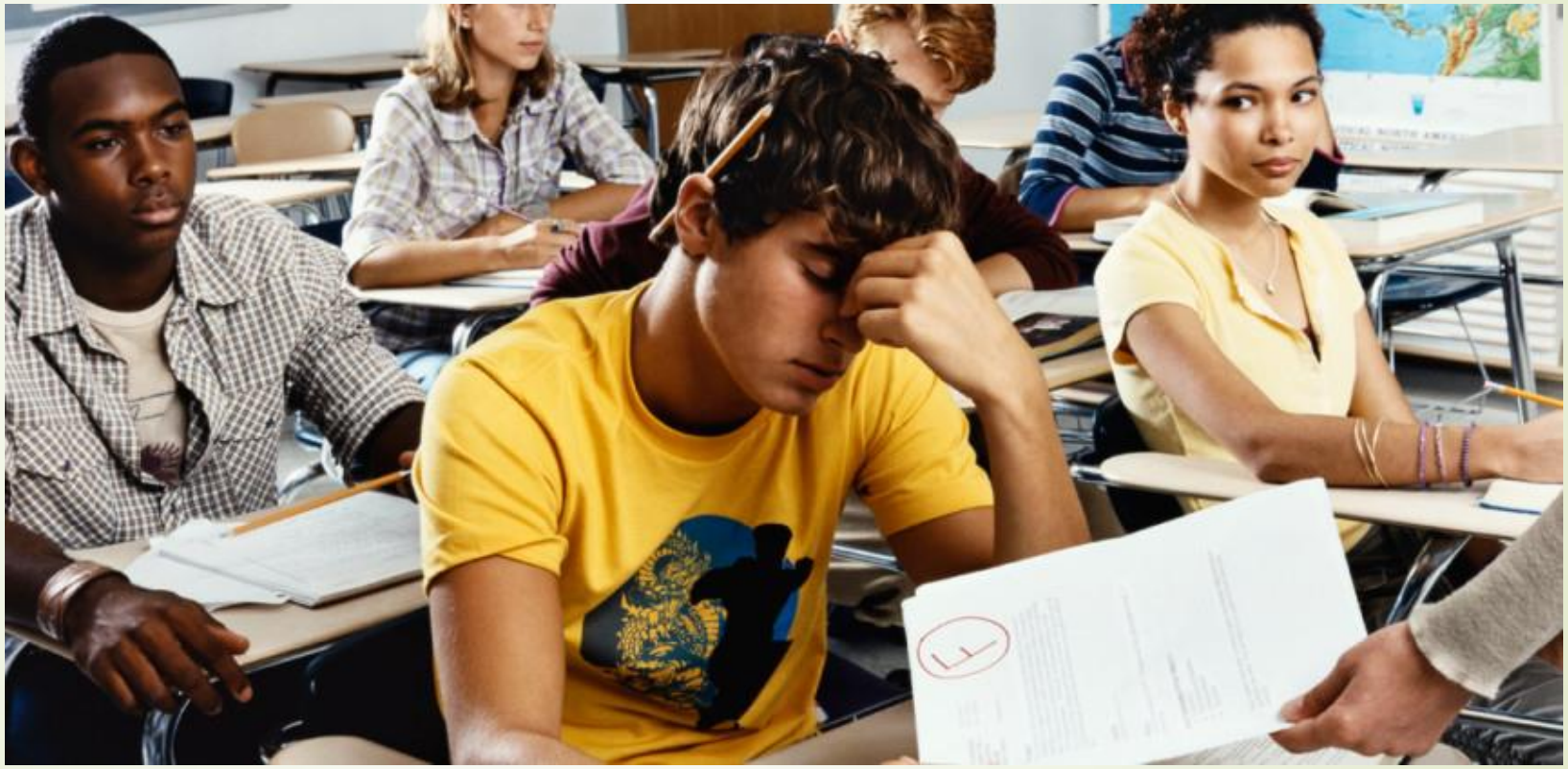
- Age, gender and temperament of the child
- Role of the child as a young carer

Emotional State of Affected Parent

- Negative emotional state can affect a child directly and indirectly
- The child may receive less psychologically support
  - Less recognition that a child is not coping well and needs help
- They may not receive adequate supervision
  - Lack of consistency in encouragement
  - Lack of consistency in discipline
- They may be the recipient of displaced anger and hostility
- They may be the victims of marital/relationship discord

Overall these children become more vulnerable to developing emotional problems, academic challenges and behavioural concerns

Child Specific Factors



Age and Developmental Stage

Primary school age	Preteen/early teen	Late teen
• Concrete understanding • Fear • Loneliness • Anger • Uncertainty • May see regression	• Focused inwards • Do more chores not very willing • Resent less time for their own interests • Struggle to show empathy at times	• Identity and autonomy stage • Recognise impact of parental illness • Readily assume more adult roles • Feel burdened • Experience distress

Gender

- Several papers have explored gender differences Norhouse et al 1991, Korneluk and Lee 1998, Faulkner and Davey 2001, Visser et al 2005
- Generally adolescent females are most often cited as the population at heightened risk for both internalising and externalising problems
- Several possible reasons including the fact that while females will often take on care giving tasks they struggle with fear of the parental prognosis as well as anger and resentment at their 'parentification'
- Thus they experience stress, anxiety and depression but are also often argumentative towards and dismissive of the ill parent

Impact of Being a Young Carer

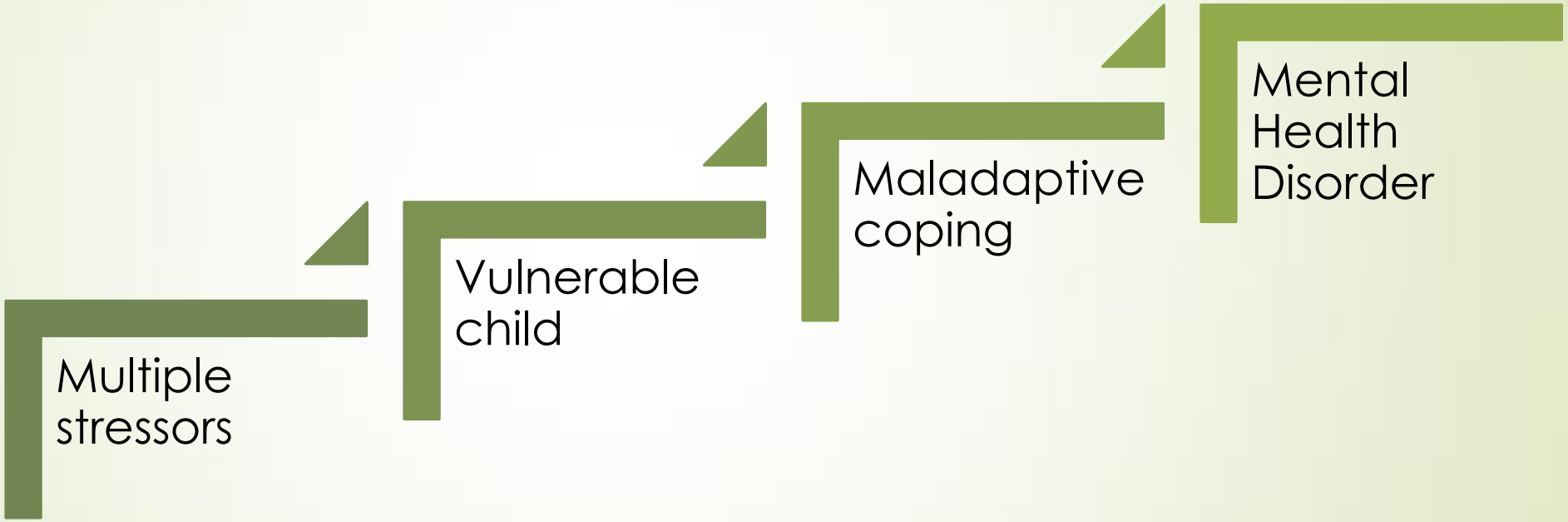

!
CAUTION

There may be unexpected benefits

- Families do draw closer together under difficult circumstances
- There can be increased mutual admiration and respect
- Children may have a greater sense of pride and achievement
- They may also demonstrate a new found maturity
- They may learn many new and useful skills

However, this is a situation in which anything can happen at anytime consequently it is very easy for children to become overwhelmed and become vulnerable to developing mental health disorder

Pathway to Mental Health Disorder



Types of Mental Health Disorder

- Mood disorder — Visser et al 2004, Sieh et al 2012, Calvo et al 2015
  - Depression
  - Anxiety
- Phobic/Adjustment disorder — Faukener and Davy 2002, Harris and Zakowski 2003
- Conduct disorder — Rodrigue and Houck 2001, Sieh et al 2010
- Substance Misuse — Diareme et al 2006, Duryea 2007


DEPRESSION

Depression in children

- As with adults children will express sadness
- They also exhibit irritability often in the form of tantrums
- They may be less inclined to enjoy usual play time activities
- At night there may be more nightmares and disturbed sleep
- We may also see some regressive behaviours
  - Fiercely independent youngsters are now more tearful and clingy
  - Separation anxiety and school refusal may occur
  - May see bed wetting in previously continent children
  - Children may seek the comfort of the parental bed more

Depression in Children II

- There may be guilt that they did something bad which may have resulted in their parent's illness
- They are more fearful in general about the health of other adults
- They are constantly worried about what will happen to them
- They may become preoccupied with dying and with death

Depression in Adolescents

Depression in Adolescents II

Points to remember

- Adolescents often present with anger/irritability rather than sadness
- They may even describe feelings of emptiness
- Self harming behaviour may be internal or external
  - May cut or overdose
  - May fight, abuse drugs, engage in under age sex
- Academic decline is often a strong indicator of difficulty
- Withdrawal from peers and peer related social activities

Screening and Early Detection

- This is especially challenging for adult clinicians whose main focus at interview is the ill parent and their treatment regime
- Depending on case complexity – literally no time available

Possible suggestions

- Delegate to other staff members e.g. clinic nurse
- Have key questions to use as a guide to check on family well being
- Consider the use of screening questionnaires
- Be alert for potential flash points at difficult times in disease course
- Refer on to support agencies or specialist mental health clinics

Screening for Depression

Key Questions

- Has any one commented on changes in your children?
- Any sleep or appetite changes?
- How are they doing at school?
- Are they still connecting with peers or similar age cousins?
- Have they said anything to you or expressed any concerns?

Key Times to Monitor

- At time of diagnosis
- After periods of extended separation – hospitalisation
- If disease state deteriorates
- If there is marital breakdown
- At times of planning for death
- Following bereavement

Screening for depression : Use of Tools

- Another possible recommendation may be the use of screening tools specially those validated in a cross section of ethnic groups
- Single paged forms completed in 10 min or less are preferred
- Child and parent forms provide useful information
- Forms can be given to the family to complete at home
- The clinician then has a chance to briefly review in session bearing in mind the context of the responses and then action plan accordingly

Screening Tools for Children and Teens

- Mood and Feelings Questionnaire (MFQ)
- Screen for Child Anxiety Related Disorders (SCARED)
- Paediatric Symptom Checklist (PSC or Y-PSC)
- Strength and Difficulties Questionnaire (SDQ)

Child Self-Report

MOOD AND FEELINGS QUESTIONNAIRE: Short Version

This form is about how you might have been feeling or acting recently.
For each question, please check (□) how you have been feeling or acting in the past two weeks .
If a sentence was not true about you, check NOT TRUE. If a sentence was only sometimes true, check SOMETIMES. If a sentence was true about you most of the time, check TRUE.
Score the MFQ as follows: NOT TRUE = 0 SOMETIMES = 1 TRUE = 2
To code, please use a checkmark (□) for each statement.

1. I felt miserable or unhappy.
2. I didn't enjoy anything at all.
3. I felt so tired I just sat around and did nothing.
4. I was very restless.
5. I felt I was no good anymore.
6. I cried a lot.
7. I found it hard to think properly or concentrate.
8. I hated myself.
9. I was a bad person.
10. I felt lonely.
11. I thought nobody really loved me.
12. I thought I could never be as good as other kids.
13. I did everything wrong.

Screening for Anxiety Disorder - SCARED

- This is a self report measure with 41 questions
- Valid for use in the 8-18 age group
- Screens for the following disorders:
  - Panic disorder
  - Generalised anxiety disorder
  - Separation anxiety disorder
  - Social anxiety disorder
  - School avoidance
- Parent version available so useful for comparison

Paediatric Symptom Checklist - PSC

- This is a psychosocial screen designed to facilitate the recognition of cognitive, emotional, and behavioural problems for ages 4 -16
- It consists of 35 items that are rated as “Never,” “Sometimes,” or “Often” present and scored 0, 1, and 2, respectively
- There is a parent version and a youth version – ages 11 and up
- Data on negative screens is considered 95% accurate
- While other data suggests that two out of three children and adolescents who screen positive on the PSC or Y-PSC will be correctly identified as having at least moderate impairment in functioning.

Strength and Difficulties Questionnaire - SDQ

- Self report tool for ages 4-17
- Parent and Teacher versions are also available
- 25 item questionnaire looking at
  - emotional symptoms
  - conduct problems hyperactivity/inattention
  - peer relationship problems
  - prosocial behaviour
- Translated into a number of languages
- Good sensitivity and specificity

Management of Mental Health in Children with a Chronically Ill Parent

Management

- Key word = Awareness
- Clinicians and treating teams need to remember that any patient is part of a family and most illness will impact on the family and kids
- Remember to ask about children and enquire if there are additional support systems in place and recommend suitable support agencies
- Encourage discussion amongst families and provide guidelines
- Clinic tool kit – child friendly literature or websites

Management - Suggestions for Parents

Questions to answer – variability depending on the condition

- What is wrong with you?
- Why has this happened?
- Will it happen to me?
- Does it hurt?
- Is it something I did?
- Is it going to last forever?
- Are you going to die?
- Who will look after me?

Management – Call the Cavalry

- Clinicians of parents cannot be reasonably expected to manage a parent's physical health and an entire family's mental health issues
- So don't try to do it on your own
- Children can access guidance counsellor's at school
- Many churches offer pastoral counselling
- Support groups often offer peer and family counselling
- Mental health professionals are available to assist as well

Management – Final Tips

- Remember that children can and do suffer with ill parents
- Encourage discussion and planning to support them
- Refer on for help

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Thank You