

Psychological Wellbeing of Children and Young People with Chronic Illness: What parents and health clinicians should know

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11 October 2019



Chronic Illness in Children

- Long term illness lead to increased stress in patients and family members
- Impact on social and emotional development in children and adolescents
- Due to changes in lifestyle, self image and peer relationships
- Examples of chronic illnesses:
 - Asthma
 - Diabetes
 - Bleeding Disorders (e.g. Haemophilia, Von Willebrand Disease, ITP)

Social and Emotional Development : Preschool Aged Children

- Emotional outbursts: negative emotions expressed as crying or aggression
- Younger pre-schoolers find it difficult to hide emotions
- Development of language: can identify feelings (e.g. happy, sad, scared)
- Basic emotional self-regulation (e.g. blocking ears or shielding eyes, self talk)



Social and Emotional Development: Preschool Aged Children

- Learn how to react and regulate emotions from adults
- Learn social skills by modelling from family members
- Extended through exposure to same age peers in preschool
- Able to recognise self in mirrors and photos
- can categorise self and others based on age, gender and physical characteristics



Chronic Illness and Psychological Wellbeing for Young Children

- Very limited understanding of their illness
- Limited language to communicate their needs/feeling unwell
- Rely on parents to interpret and communication on their behalf
- Higher risk of developing separation anxiety
- Increase in emotional outbursts to be expected due to developmental stage, or could be due to illness
- Rule challenging behaviours can develop due to feeling restricted (e.g. lifestyle such as play)
- Procedural trauma/ negative associations



Social and Emotional Development: Primary School Aged Children

- Increased understanding of the dangers of the world/ being hurt
- Common fears include academic performance and rejection from classmates
- Increasing comparisons to classmates and seeking peer approval
- However, family still maintain a key role in emotional support
- Gains in internal emotional regulation skills and problem solving
- Thoughts about emotions
- Reduction in emotional outbursts as a result



Social and Emotional Development:

Primary School Aged Children

- Learn to follow rules to gain approval and avoid punishment
- Developing empathy and concern for others as emotional understanding improves
- Self esteem: incorporating personality traits (positive and negative), making social comparisons
 - E.g. school performance, social relationships, physical competency/ skills, appearance



Chronic Illness and Psychological Wellbeing for Children

- Increase in understanding about illness
- Health related worries
- Increase in rule challenging behaviours
- Notice differences to peers
- Exclusion from peers and/or activities
- Feelings of sadness/ loneliness
- Change in interactions with other adults
- Conflict with parents or siblings
- Sense of unfairness or injustice if treated differently from peers or siblings
- Feelings of anger



Social and Emotional Development :

Adolescents/Young people

- Development of identity and self esteem– personality and context (e.g. peer groups, relationships, achievements)
- Increasing importance of peers/friendships
- Developing independence from family
- Parents provide emotional support as a secure base to explore the world with confidence
- Exploring relationships and vocational choices
- Worries about the future



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Chronic Illness and Psychological Wellbeing for Young people

- Impact on quality of life
- Feeling different or excluded from peers
- Illness incorporated into sense of self
- Increase in understanding of longer term nature of illness
- Awareness of the long term nature of their illness
- Feelings of hopelessness
- Implications for future
- Health related anxiety



Chronic Illness and Psychological Wellbeing for Young people



- Longer term impacts of procedural trauma
- Parental over protection
- Increasing conflict with parents
- Rebelling against health advice
- Rule challenging behaviours
- School /teacher stressors

What can parents do to help?

- Provide a supportive home environment (low conflict and high warmth)
- Key role in providing emotional support/ reassurance/ secure base (especially for younger children)
- Communication!
 - Parents are the key communication link between child and health professionals
 - Advocating for your child. You are the expert about your child.
 - Younger children: reading and modelling from parents (use of words to describe feelings)
 - Older children and young people: opportunities for conversations

What can parents do to help?

- Role for distraction/ diversional interventions for younger children
- Help the child/ young person to develop personal competencies for self esteem/ identity separate from illness
- The child is not defined by their illness
- Opportunities to develop peer connections
- Importance of school attendance



What can parents do to help?

- For adolescents/ young people:
 - Balancing autonomy/independence with ongoing monitoring and support
 - Development of self efficacy and assistance to maintain adherence to treatment
 - Increased monitoring required in comparison to peers without a chronic illness
 - Research evidence that ongoing parental involvement improves adherence with illness management
 - Also reduces health related anxiety and conflict
 - Importance of trust

What can Health Professionals do to help?

- Health professional concern that parental involvement decreases self management in young people , however research indicates otherwise (e.g. Martine & Helgeson, 2017)
- Importance of involving parents in illness management – balancing independence with parental support
- Psychosocial screening and multidisciplinary interventions/ supports
- Collaboration with schools

When to refer to Psychology or other Psychosocial Interventions

- Look for signs that could indicate decline in emotional wellbeing:
 - Changes in sleep and appetite
 - Withdrawal from friends and previous enjoyed activities
 - Headaches and stomach aches
 - Increase in irritability, anger or fatigue
 - Increase in rule challenging behaviours
 - Getting into trouble at school
 - Difficulties concentrating or decline in school grades

Role for Psychologists

- Importance of inclusion in Multidisciplinary team
 - Consultation/advice to treating team
 - Assessment of emotional and social development
 - Assessment of behavioural problems and emotional/ mental health concerns
 - Psychological interventions
- External referrals to community-based and private psychologists



Psychological Interventions for children/adolescents with chronic illnesses

- Family based interventions
- For younger children: distraction/diversional interventions, behavioural interventions such as positive reinforcement
- Older children/young people: talking based interventions: Cognitive Behaviour Therapy (CBT)
- Additional interventions for Adolescents:
 - Motivational Interviewing
 - Acceptance and Commitment Therapy (ACT)
 - Distress tolerance strategies and Mindfulness

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- Multidisciplinary clinics – including Clinical Psychologist, Social Worker and Child Life Therapist
- Psychosocial screening- Quality of life (CHO-KLAT, PedQL-SF), behavioural problems and emotional/mental health concerns (PSC)
- Clinical Nurse Specialist (CNS) facilitated 'fun days' – e.g. 'Mario Kart Challenge' and 'Campus Scamper'



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Acknowledgements:

Jaime Chase, Clinical Nurse Specialist

Dr Janis Chamberlain, Paediatric Haematologist

Kristy Iuliano, Social Worker

Veronica Oakley, Child Life Therapist

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