

When two worlds clash - Normal life and self-management regimens

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A B C D E

- **A** is for adolescent which is the second decade of life and the most important developmental stage after the first two years of life
- **B** is for brain "an organ of soft nervous tissue contained in the skull of vertebrates, functioning as the coordinating centre of sensation and intellectual and nervous activity"
- **C** is for chronic illness, any condition which cannot be prevented by vaccines or cured by medication
- **D** is for drugs and other therapies which need to be consistently and regularly taken or performed to keep chronic illness under control = **self-management**
- **E** is for energy conservation which is important for many young people with chronic conditions who want to achieve everything that their peers achieve

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A is for Adolescence

Necessary to becoming a mature, independent, functioning adult

Adolescence is hard work with tasks that should be attempted and achieved to the best of a young person's ability

For many young people there are barriers to completing these tasks; one such barrier is chronic illness

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Universal Teen To Do list

- Accept my body and my gender and my sexuality
- Integrate with and get on with my peers
- Nurture loving, caring relationships and one day form a new family unit
- Achieve autonomy and independence from my family
- Educate myself and plan for a future vocation
- Become financially independent
- Develop my social skills and competency so I can be part of my community
- Understand and keep to socially responsible behaviours
- Develop my own set of beliefs, values and ethics
- (And have fun and excitement and new experiences and some more fun and not miss out on anything)

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The limbic system

- A group of deep brain structures close to the thalamus
- In all mammals
- Made up by hippocampus, amygdala, gyrus fornicatus
- Associated with emotion, motivation, behavior
- **Driver for survival**


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Teen Brain change - the big picture

Events - years	10 - 14	15-19	20 - 24
Puberty hormones rise			
Synapses proliferate			
Synapses are pruned			
Myelination of nerve fibres			
The limbic system matures	*****		
Growth of corpus callosum			
Maturation of prefrontal cortex		*****	*****

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Putting it all together
Adding in chronic illness



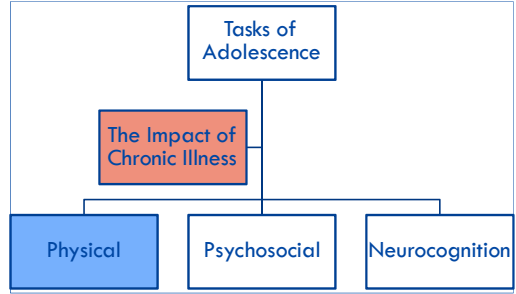
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C is for Chronic Illness

- Asthma
- Obesity
- Diabetes
- Epilepsy
- Inflammatory bowel disease (Ulcerative colitis, Crohn)
- Cystic fibrosis
- Long term effects of cancer therapy

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Chronic Illness & the Tasks of Adolescence



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    graph TD
      A[Tasks of Adolescence] --> B[The Impact of Chronic Illness]
      B --> C[Physical]
      B --> D[Psychosocial]
      B --> E[Neurocognition]
    
```

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Physical effects of Chronic Illness

- Delay in puberty
 - Out of step with peers
- Loss of a body part
- Altered appearance
- Looks 'normal' - **hidden disability**
- **Effects of inadequate treatment on physical and mental wellbeing**
- **Lack of physical energy**

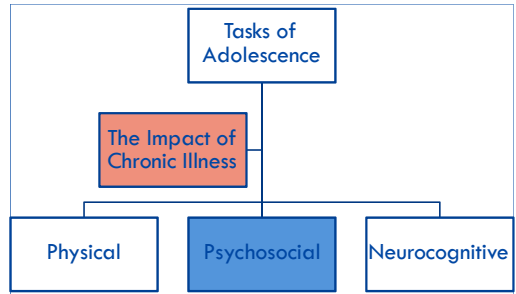
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Universal Teen To Do list

- **Accept my body** and my gender and my sexuality
- **Integrate with and get on with my peers**
- Nurture loving, caring relationships and one day form a new family unit
- **Achieve autonomy and independence from my family**
- Educate myself and plan for a future vocation
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C is for Chronic Illness



```

    graph TD
      A[Tasks of Adolescence] --> B[The Impact of Chronic Illness]
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      B --> D[Psychosocial]
      B --> E[Neurocognitive]
    
```

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Psychosocial effects of Chronic Illness

- Being different & the need to be seen as normal and the same
- Limited access to peer group
- Over-protection
- Increased health risk behaviours
- Poorer mental health
- Impact of culture and socio-economic status

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Universal Teen To Do list

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Chronic Illness & Neurocognition

```

    graph TD
      A[Tasks of Adolescence] --> B[The Impact of Chronic Illness]
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```

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Chronic Illness and the Effects of Normal Brain Development

- Distancing from the diagnosis
- Experimentation and less adherence to therapy regimens – **health risk behaviour***
- Conflict with parents/carers around therapy regimens - **autonomy**
- Gradual recognition what chronicity truly means – **neurocognitive development**
 - Depression
 - Anxiety

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Self-management in Chronic Illness

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The theory of Planned Behaviour; why we choose to do what we do and why our patients do not always do what we believe is right for them? (Icek Ajzen 2006)

Behavioural beliefs link action to outcome
Attitude toward the behaviour might not reflect behavioural belief
Normative belief is what a person perceives important persons in their life think they should do
Subjective norm is perceived social pressure
Control beliefs are personal beliefs about mastery (locus of control)
Perceived behavioural control is how effective a person thinks they will be

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Adolescence and its impact on illness/disability management

Health Risk Behaviours – and taking control of their own illness self management

- **Adolescence – health risk behaviours**
 - Smoking and chronic lung disease; asthma, cystic fibrosis
 - Eating the same as everyone else: coeliac,
 - Alcohol and chronic liver disease
 - Mixing illicit drugs with prescription drugs
 - Playing contact sport with only one functioning organ of a pair (kidney, eye)
 - Unprotected sexual activity 'because if you've had cancer you can't get pregnant'


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Helping young people to improve self-management

- Understand their viewpoint
- Increase knowledge around their condition
- Use goal setting
- Work with their medical team to achieve the simplest regimens possible

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Energy conservation



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Energy conservation

- Adequate sleep
- Priority setting
- Scheduled rest – down time
- Keeping on top of therapy regimens
- Confiding in trusted friends

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Transition to Adult Care




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A binary health system

Adults	Paediatrics (Children)
<ul style="list-style-type: none"> • Expert at battling decline, senescence and death 'Stop bad things' • Individuals expected to function autonomously • Multidisciplinary teams more limited • Limited experience in adolescent and young adult issues 	<ul style="list-style-type: none"> • Focus on healthy growth and development • Less discussion of longer term morbidity • Care is family-centered with major role for parents/carers • Multi- and interdisciplinary care • Not always trained to deal with adolescent issues

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Transition services in NSW



- www.trapeze.org.au
- <https://www.aci.health.nsw.gov.au/networks/transition-care>
- Both websites have resources and information

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What next?



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What can we all do?

- Understand the importance of adolescence
- Support the timely achievement of the tasks of adolescence
- Advocate for young people – ‘their illness does not define them’
- Assist them with timetabling and general self management
- Support their transition to adult health care

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