

COPING WITH CHRONIC ILLNESS

Claire McKinley, MD



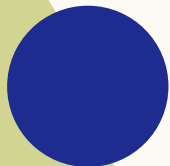
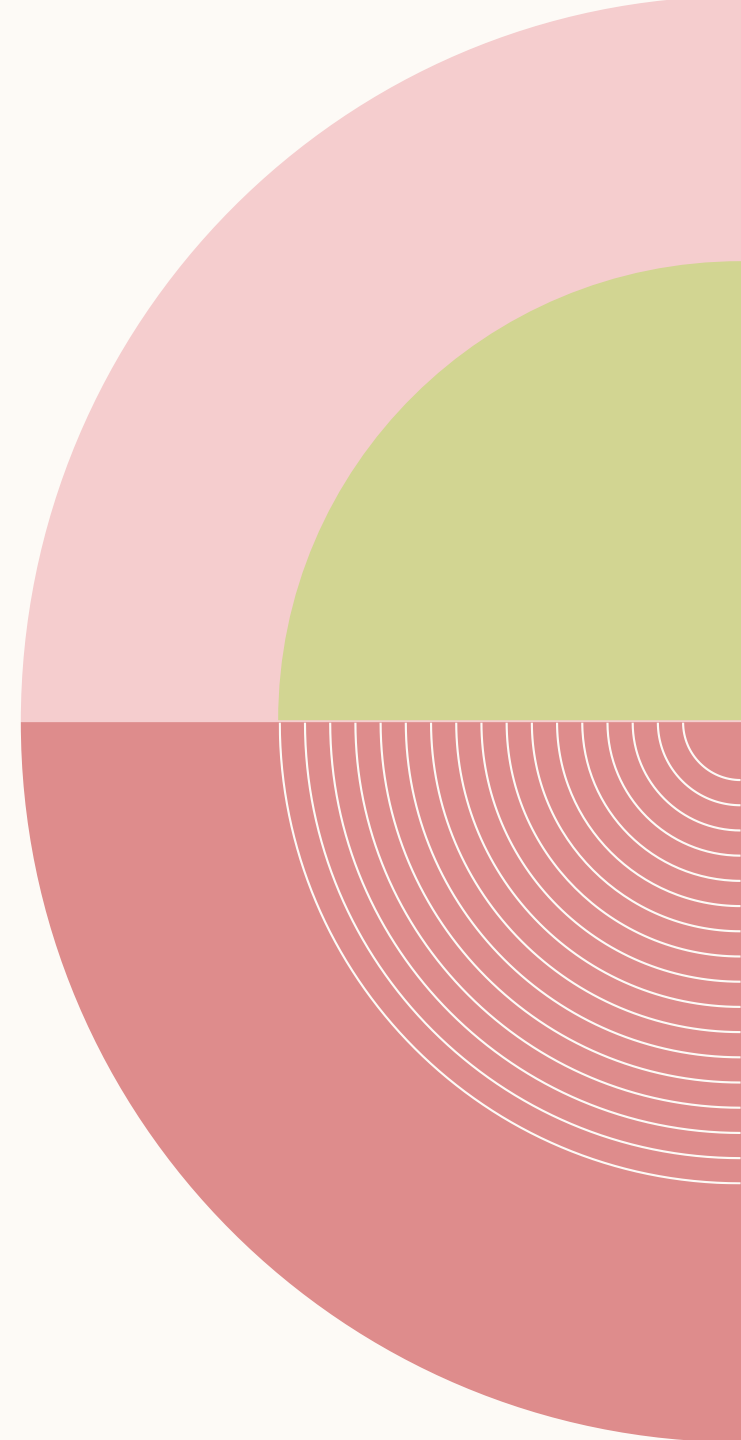
OVERVIEW


1. Grief and coping with chronic illness
2. Differences in grief and coping: children, teens, adults
3. Signs of a need for professional services
4. Tools and resources for support



**GRIEF:
COPING WITH A
CHRONIC ILLNESS**

“TYPICAL” GRIEF





“ The reality is that you will grieve forever. You will not ‘get over’ the loss...you will learn to live with it... You will be whole again but you will never be the same. Nor should you be the same. ”



**GRIEF AND COPING:
CHILDREN, TEENS &
ADULTS**

EXPRESSIONS OF GRIEF



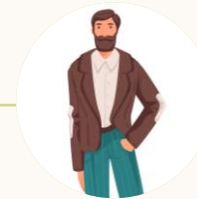
CHILDREN

- “Magical thinking”
 - Guilt
 - Cure
- Regression
- Anxiety
- “People pleasing”
- Embarrassment/shame



TEENS

- Embarrassment/shame
- Humor (in excess)
- Taking adult roles
- Risky behavior
- Easily distracted
- Thoughts of death or suicide



ADULTS

- Anger outbursts
- Guilt
- Appeasement
- Numbness
- Controlling behaviors

TYPICAL DEVELOPMENTAL TASKS

Erikson's Stages of Psychosocial
Development

Infancy

- Trust vs mistrust

Toddlerhood

- Autonomy vs shame

Preschool

- Initiative vs guilt

School age

- Industry vs inferiority

Teens

- Identity vs confusion

Early adulthood

- Intimacy vs isolation

Middle age

- Generativity vs stagnation

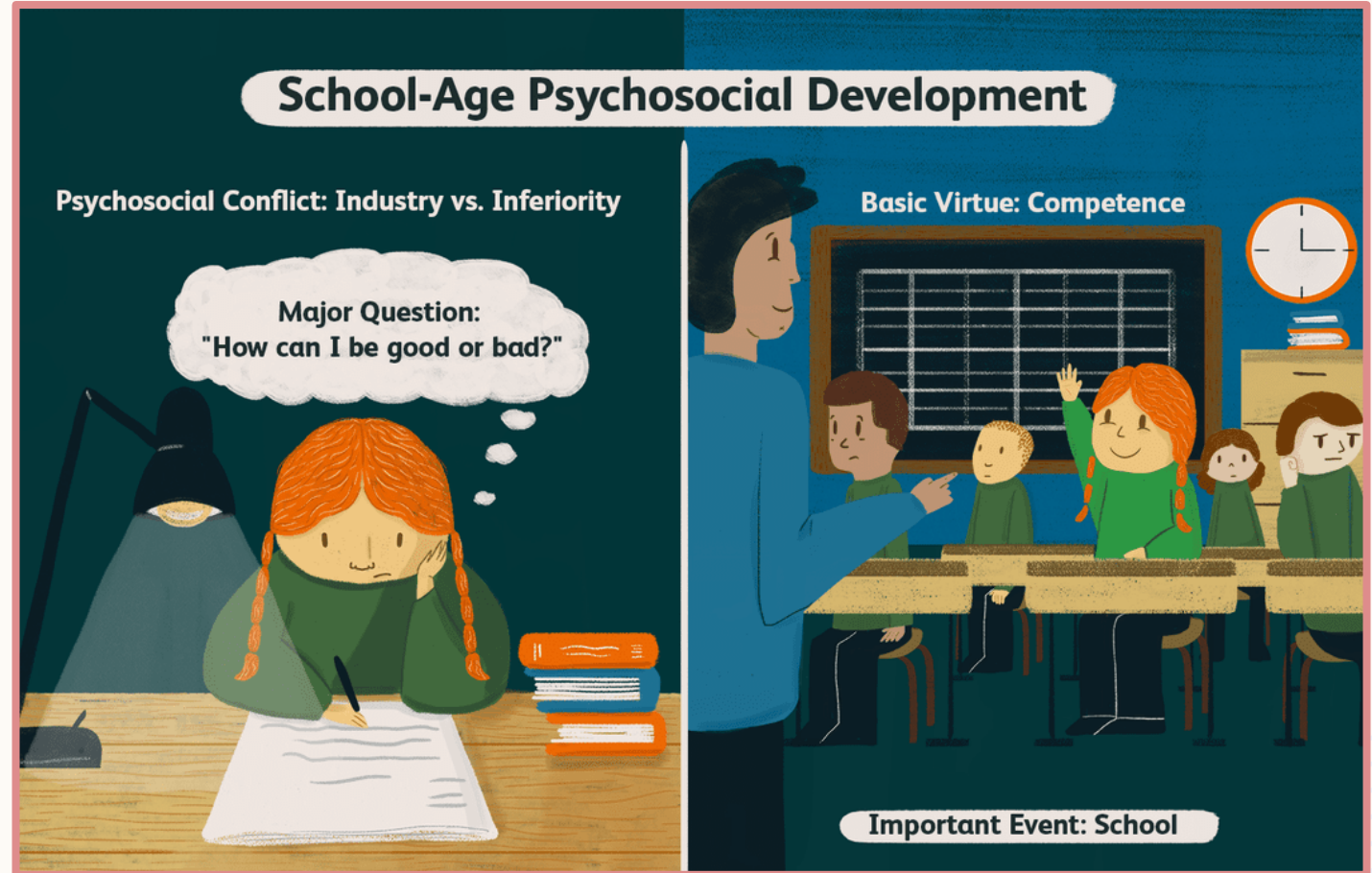
Late life

- Integrity vs despair

INDUSTRY VS INFERIORITY

Child faces increasingly complex tasks; by facing and completing them the child develops patience and self-belief

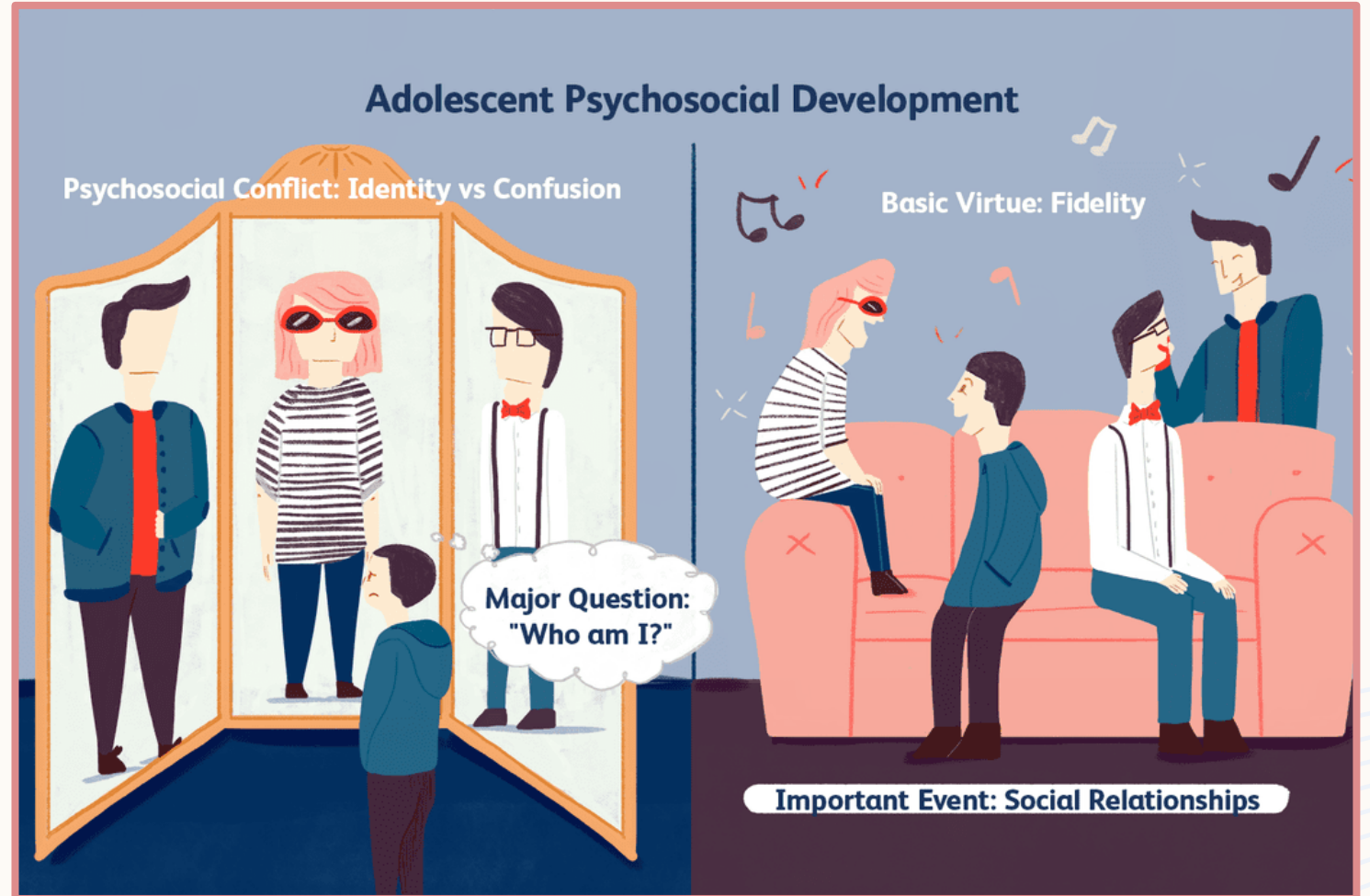
- Roughly ages 6-12
- School, teachers and peers important
- Often academically focused
- Child may feel ashamed of differences from peers



IDENTITY vs CONFUSION

Developing a sense of self that is separate from the family unit. Preparing for adult relationships and responsibilities. “Who am I?” “Who do I want to be?” “What are my values?”

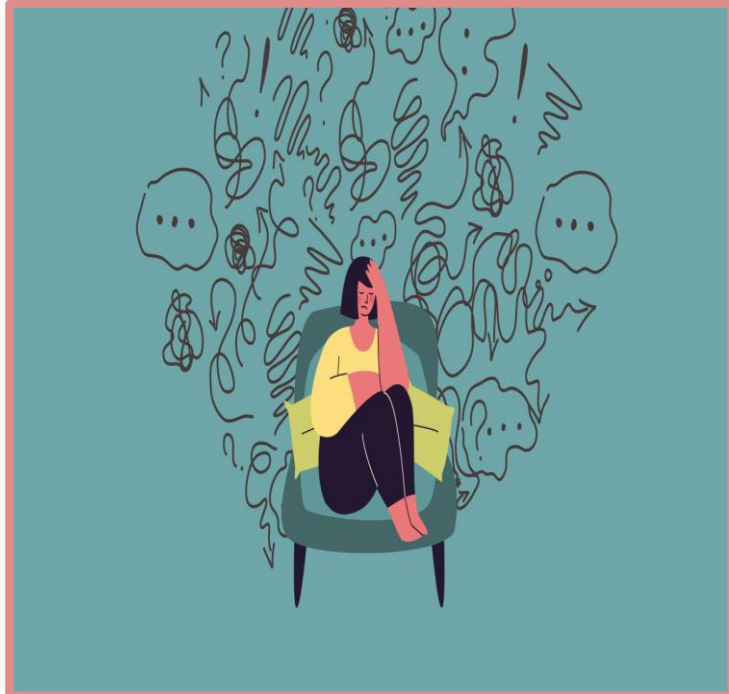
- Peers increasingly important
- Some degree of rebellion is typical and healthy
- Social media is a potential pitfall





**WHEN TO
CONSIDER
ADDITIONAL
SUPPORT**

WARNING SIGNS



Grief or behavior changes seem to last longer than 6 months

Any “clinically significant distress or impairment”

Power struggles

Younger age at diagnosis

Thinking about death



PROFESSIONAL SUPPORT



EARLIER IS BETTER

Age at diagnosis
Problem course



FOCUS ON TRANSITIONS

School transitions
“Big” birthdays
Disease transitions



FOR THE WHOLE FAMILY

Individual therapy
for siblings
Therapy or other
support for parents



POWER STRUGGLES

Family therapy
OR
Everybody in
individual therapy



THOUGHTS OF DEATH

Ask and listen to
involve the right
expert



**TOOLS AND
RESOURCES**

GENERAL EDUCATION (MENTAL HEALTH)

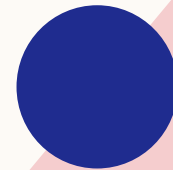
www.kidshealth.co.nz

- Reader-friendly info on child development

www.nhs.uk

- “Health A-Z”

- “Medicines A-Z” (use generic names)

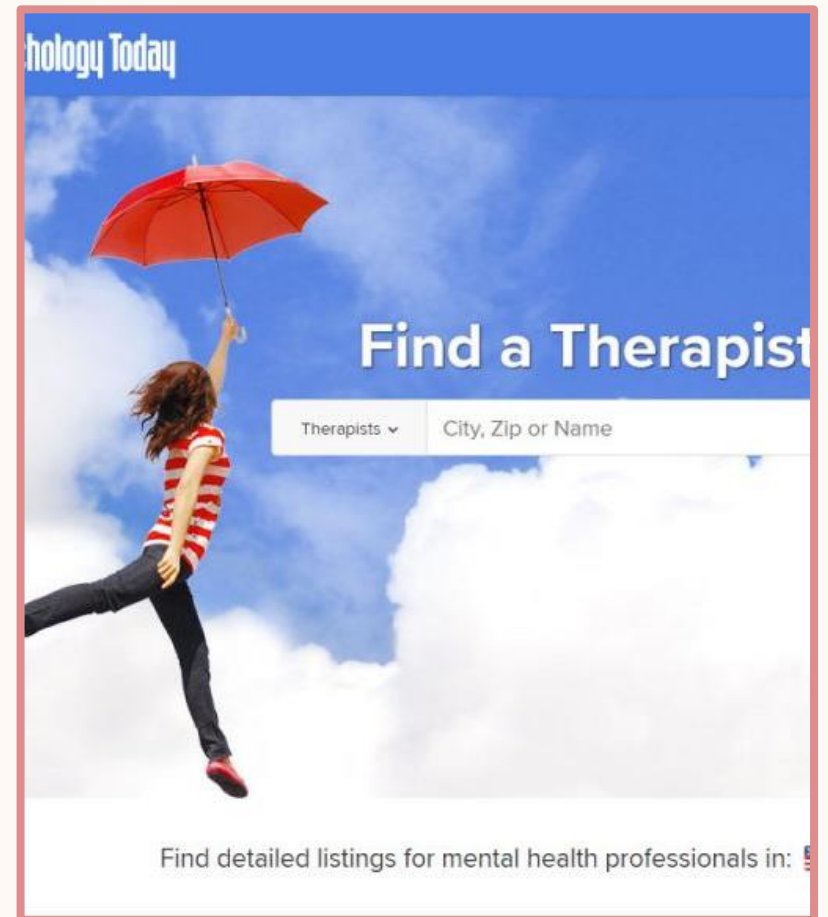


“FIND A THERAPIST”

www.psychologytoday.com

- “find a therapist”
- filter by location

The best way to find a therapist is still word of mouth: from your doctor or your friends



PEER SUPPORT

- aakp.org (US)
- www.kidney.org/peers (US)
- www.rsnhope.org



SUMMARY

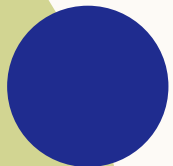
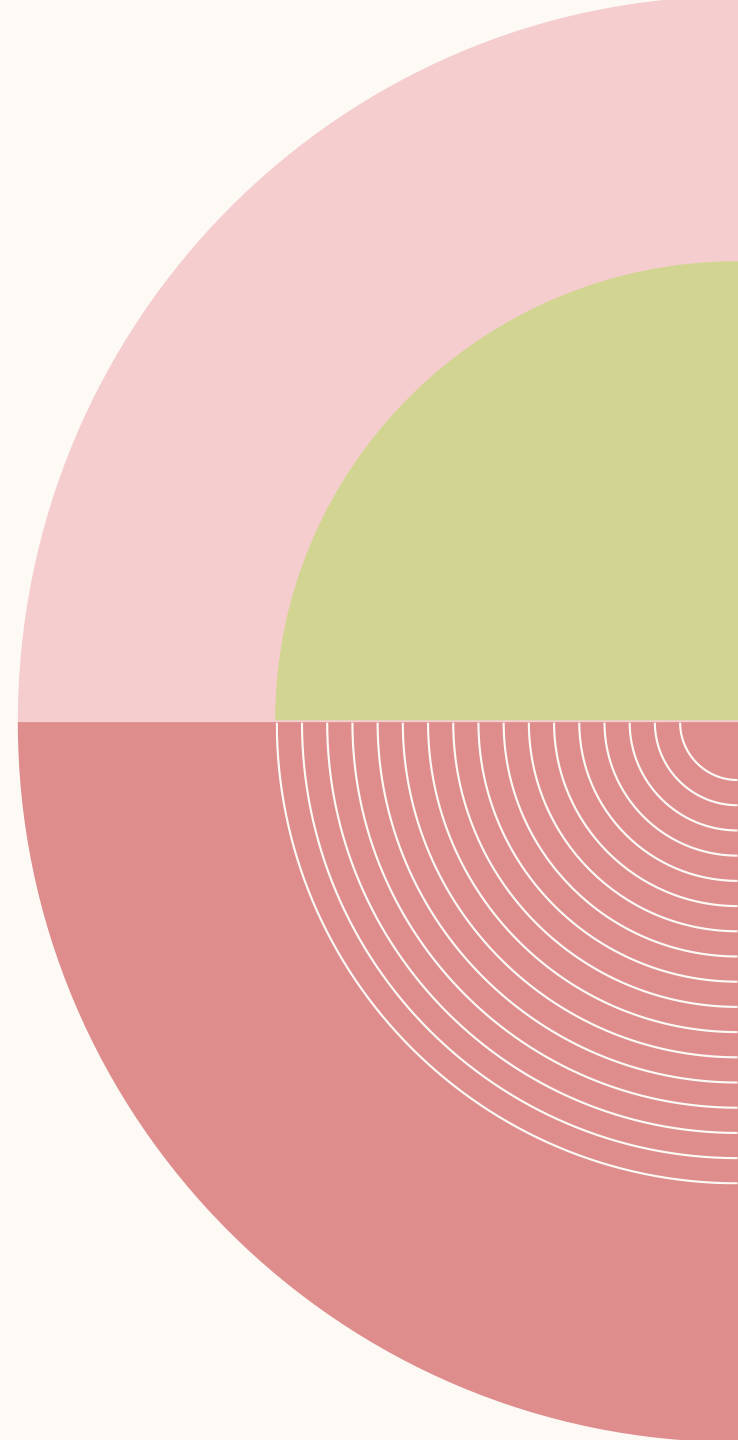
Grief and coping is different for everyone, and especially different for different age groups

Help your child find ways to challenge themselves and grow

Know your resources before you need them

When thinking about support, consider everyone in the family

- Earlier is better (resources permitting)
- Peer support is valuable
- Make sure caregivers have their own support



THANK YOU

