

# CARDS FOR HUMANITY

Human: the emotional, social, cultural and personal dimensions of illness experiences.

Designed for clinicians working in children's rehabilitation and multidisciplinary neuromuscular settings. These cards aim to help clinicians explore and improve the 'human' aspects of living with neuromuscular conditions for young people and their families.

In a 4-year Canadian study, clinicians working in children's neuromuscular care were facilitated to consider how their care did/did not address the human aspects of living with disability. They noted a mismatch between the importance clinicians placed on the human aspects and what actually happened in clinics. These cards contain the key ideas the clinicians and researchers identified as important to highlight for others working in the area.

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# HOW TO USE

## Blue cards (use with children/families)

- Use as prompts to help raise potentially uncomfortable topics with children and families.
- Place cards in front of children and/or families, ask them to identify any ideas that they would like to explore.

## Green cards (for clinicians)

- Use for discussion points at team meetings.
- Keep them in a visible place so clinicians can look through them.
- Choose a card to keep at your desk or on your lanyard for a week. Swap with a colleague every week.



# HAVING FEELINGS

However you feel is okay.



# TODAY I FEEL...



Point to one that looks most like  
how you feel.



# I'D LIKE TO KNOW...

but I'm not sure how to ask.





# I'D LIKE TO TALK ABOUT..

- friends.
- the future.
- family.
- being teased.
- dating.
- what is going to happen.
- something else....



# HAVING FEELINGS

However they feel is okay.





# HAVING FEELINGS

- Create a safe space for expressing a range of emotions (including anger, sadness and grief).
- Acknowledge emotions (not only positive ones).
- Clinicians will often need to initiate discussions about 'difficult' emotions.

**Use the corresponding client card to facilitate discussions.**





# DIFFICULT TOPICS

"I'd like to know.....?"



An orange triangle pointing downwards, with a white circle inside it.

# DIFFICULT TOPICS

Some important conversations can be uncomfortable, e.g.:

- Puberty, sex, sexuality
- Disability stigma, bullying
- Decline, death, dying
- Disease progression, the future

Consider upskilling if you find introducing any topics difficult.

**Use the corresponding client card to facilitate discussions.**

A green triangle pointing to the right, with a rounded tip.



# RISK..

needs to be considered  
in a more complex way.





# RISK

- How much risk is okay?
- Risks can be physical, but also psychological and social.
- It's hard to let go of feeling responsible for a client's wellbeing.
- Can we let kids be kids?



# DO YOU NEED CARE?

Check in with yourself  
and others in your team.





# DO YOU NEED CARE?

- You need support to effectively care for clients, their families and others.
- Emotional client discussions can impact you.
- Experiencing client decline and loss can reduce your resilience.
- Working within a system can create moral distress.

Find support through friends, colleagues, organizational networks and any other self-care strategies.



# ASSUMPTIONS

Everyone has their own ideas about what is best.





# ASSUMPTIONS

- These are reflected in the goals you think to be important or valuable (e.g. independence, mobility, physical safety).
- Your assumptions might be different from other people's.
- Your assumptions can affect perceptions and impact care.
- They can signal to clients what is expected, acceptable or 'normal'.

If you are aware of your assumptions, you can decide what is helpful. You may need to let go of your assumptions to provide good care.





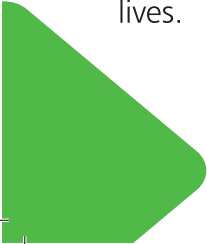
# CRITICAL REFLEXIVITY...

involves considering the impact of our assumptions, values and actions on others.





# CRITICAL REFLEXIVITY

- Reflexivity often requires time, space and facilitation.
  - Create time to think about the human aspects of care.
  - Both team and individual reflexivity is needed.
  - Think about how clinical care can address the emotional, social and personal aspects of clients' lives.
- 



# CREATING SOCIAL CHANGE

Your clinical knowledge has power.





# CREATING SOCIAL CHANGE

- The burden of change often falls on clients/families.
- As a clinician, your voice has power.
- Important areas for change include:
  - ▶ reducing disability stigma
  - ▶ improved accessibility
  - ▶ better service availability



# LANGUAGE IS IMPORTANT

Acknowledge that language  
has power.





# LANGUAGE IS IMPORTANT

- Foster awareness of the unintended effects of what you say.
- Unintentional bias and assumptions can be conveyed through language.



# FLEXIBILITY

Creating adaptable and open ended approaches to clinic visits.





# FLEXIBILITY

- Facilitate input from the clients and families.
- Balance 'best practice' care with individual family priorities.
- Be open to changing clinic routines.
- Foster creative solutions.





# UPSKILLING FOR 'HUMAN' FOCUSSED CARE





# UPSKILLING

Enhance the human aspects of client and family lives by improving understanding of:

- diversity and inclusion
  - spirituality, meaning making, religion
  - addressing and supporting 'negative' emotions
  - self-care for clinicians
  - coping with client death and decline
  - sexuality and disability
- 



# BALANCING MEDICAL & 'HUMAN' CARE

Individualize care to balance  
'human' and medical aspects  
of living with disability.





## BALANCING MEDICAL & 'HUMAN' CARE

- Avoid sidelining 'human' aspects such as the emotional, personal, moral.
- Are routine assessments always needed?
- Create procedures to ensure 'human' aspects are considered and addressed.