

Families Moving Forward: How **professionals** can support **families**

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Outline

1. Understanding your professional
2. Professionals outlook on disability
3. Key Roles of Professionals



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Understanding Your Professional

- Doctors need to recognise how important their opinion is from perspective of the parent
 - What the doctor says at the time of breaking the “bad news” is firmly etched in some parents’ hearts and minds, often influencing their long term outlook
- Other professionals in disability better trained than doctors
 - 1hr development, 1 hr CP, 1 Other disabilities, Rest on the job

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1/2

Understanding Your Professional

- Not trained adequately in breaking bad news
 - Tend to shy away from painful situations
 - Illness/disease trained with focus on cure. When cannot heal, feel defeated and may distance themselves.

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Understanding Your Professional

Professionals are also disabled

Disabled in their training

Disabled in their communication

Disabled in their outlook

**It is our choices that show
what we truly are,
far more than our abilities.**

—Professor Dumbledore—

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Professionals Outlook on Disability

- Medical model or “Clinical model” tends to dehumanise the relationships
 - Tend to look at people as patients with problems or diseases that need fixing
- Trained to be “objective” i.e. to be clinically detached from patient
- Lack of spiritual dimension in training
- Do not explore their own outlook on disability
 - Many false societal beliefs influence doctors

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Professionals are people first (professionals 2nd)

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Key Roles of Professionals

- **Attentive Listener & Friend** (therapeutic bond)
- **Offer meaning/truth**
 - Speak truth (despite it not always wanting to be heard)
 - Deal with unspoken questions
- **Offer direction/support**
 - Connect with other families
 - Connect with services
- Help advocate for services with families



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Key Roles of Professionals

Attentive Listener & Friend

- Build a “therapeutic bond” with them & become their friend
- By being an attentive listener and friend
- Does not diminish our care or make us less “objective” but rather enhances our care

**It is not about how much we do
but about how much we love**

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“When we honestly ask ourselves which person in our lives mean the most to us, we often find that it is those who, instead of giving advice, solutions, or cures, have chosen rather to share our pain and touch our wounds with a warm and tender hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing, not curing, not healing and face with us the reality of our powerlessness, that is a friend who cares.”

Henri J.M. Nouwen



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Key Roles of Professionals Attentive Listener & Friend

- Listening to parents pain
- Key questions in parents hearts at time of diagnosis:
 - “Why has this happened to me?”
 - “Was this due to something I have done?”
 - “How do I cure my child?”
 - “Will he go to normal school?”
 - “Only my child is like this.”
 - “My life is trapped!”
 - “What will happen to my child when I die?”
- Guilt, Fear, Grief, Stigma

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Key Roles of Professionals Offer Meaning/Truth

Play a key role in supporting them by:

- Offering an honest opinion tempered with compassion
- Not merely describing the disability but also the strengths of the child
- Not just outlining the challenges but also the hopes



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Key Roles of Professionals Offer Direction/Support

- Connect with other families
- Connect with services

- Help advocate for services with families

Key: Develop a practise where Families see the same professional most of the time

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For Professionals (How To)

- Develop a practise where parents see the same professional most of the time
- Undergo internal change (spiritual deepening of personhood) which is more important than external change (technical advancement & skills)
- Integration of true spirituality into practice
- Treated every parent as a unique individual
- Offered time/space necessary to families

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Summary

1. Attentive Listener & Friend
2. Speak Meaning & Truth
3. Offer Direction & Support
4. Advocate
5. Be There



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