

Working with families living with motor neurone disease utilising the 'Think Family' model-emerging themes

Background and Aims

In 2017 the Manchester MND Care Centre obtained funding (4 years) from the Motor Neurone Disease Association for someone to work with families affected by MND, not only looking at the needs of the person with MND but also their wider family, including any children.

I worked with a number of families with a variety of different family structures

A number of themes emerged, such as diagnosis, changing symptoms, quality of life, making memories, bereavement. I researched resources and information to support families.

I would like to share some of these themes and useful resources with the COP. In the hope this will increase the knowledge and confidence of those working with PWMND to 'pick up on the cues' and 'ask the questions'



Salford Care Organisation
Northern Care Alliance NHS Group

Diane Aldridge, Social Worker
Greater Manchester MND Care Centre
E: diane.aldridge@srft.nhs.uk

Themes

1. Using the Think Family Approach (Care Act 2014)

Consider asking the following questions

Who else lives in your house?

Who helps with your support and who is important in your life?

Is there a child in the family?

Does a parent need support in their parenting role?

Is there anyone you provide care or support for?

2. Sharing diagnosis with family

The Pros v Cons of telling children

Resources to help newly diagnosed patients think about this. Helping them make an informed decision about sharing their diagnosis.



3. How is MND impacting on their life? Focus on Quality of life

Continuing in employment – Access to Work

Continuing with hobbies/interests/ or finding new ones

Maximising income- welfare rights advice, grants

Driving- driving assessment centres, Motability scheme

What resources are available for families?

Wheels for All, Special Effect

4. Changing symptoms

Time when more equipment might be coming into the home (Hospital bed, NIV machine)

Think Family- situation may become more apparent to children, they can be worried or anxious

Use this opportunity to check

ASK 'Are the children okay with this? Do they need more support or information?

Think Family- Contingency Planning

ASK 'Who looks after the children in an emergency?'

ASK 'What would the children do in an emergency?'

ASK 'Does School or College know that the family is affected by MND?'

Help and support provided by school. (Pastoral care, referral to psychological support)

Young Carer's Support.

Support provided by Motor Neurone Disease Association

CONSIDER Does school need more information about MND?

Making Memories

Building memories - supporting families to do things together.

How can we support this? (practical, financial, information)

Memory Boxes – Pilot with Motor Neurone Disease Association.



Bereavement Support

What support is available, both national and local?

Examples:

Winston's Wish, Child Bereavement UK -Support for Young People Widowed and Young- for those who have lost a partner before their 51st birthday

Cruse Bereavement Care – Help & Hope for Men Living with Loss

Evaluation

Focus on qualitative and theme based analysis. I developed an evaluation form and used supervision for reflection.

Importance of finding out what is important to the person with MND, focusing on quality of life.

Drawing on training such as 'enhanced communication skills' allowed me to explore with families what might happen in the future, to be informed and confident enough to ask the questions and begin conversations as outlined above.

Conclusion

Using the Think Family approach means that we can improve our understanding of a situation and help families access the support and resources they need.

We can ask the questions, we don't have to have the answers!

Small things can mean so much

- Changing the time of clinic appointment so can get back for the kids coming home from school.

- Physio showing me some exercises I could do with the football and the kids!

- Hiring a wheelchair Accessible vehicle meant we could go on holiday

I hope that the work has been able to demonstrate meeting NICE NG42 (1.2.3) information on diagnosis, (1.2.7) Time to discuss diagnosis, (1.2.9) advice re carers assessments, (1.6) psychological support

Recommendations

I hope to raise awareness of the 'Think Family Approach' through presentations to the community teams we work with across Greater Manchester.

To develop and share the road map of key themes