“Children, Young People & Whole Family” Service Development

Bringing our strategy to life
Opportunity to make a difference

Supporting families adjusting to the distress of a life shortening diagnosis.

Ensuring children are not at risk, if their needs are marginalised by the huge changes and challenges that MND brings.

Support the most distressed families.
Respect the most resilient.
Engagement & Consultation

Scoping the current landscape

- RCDA workshops
- Focus groups for CYP affected by MND (aged 4-17 years)
- Interviews with parents with/affected by MND
- Questionnaires with parents and CYP
- Consultation with a range of HSCPs
- Consultation with specialist organisations and services
- Review of information already held
- Graffiti Wall – ‘me, my family and MND’
What they told us...

- Support is needed at an appropriate time, the earlier the better
- Signposting is needed to appropriate support services
- Children first, not just young carers or the child of an ill parent
- Use of language is important
- Needs are individual
- Advocacy and having a voice
- Family members and children are not an afterthought for support
- Some families receive no support for affected CYP
What they want...

- To have an opportunity to make memories
- To give back – volunteer, fundraise etc.
- Support to speak with other affected children about the diagnosis and death
- To be signposted to appropriate services (time is not always a luxury)
- To ensure school is aware as they are best placed to offer support
- To find ways to cope
So what’s the big plan?

- Memory making days and a ‘How To Guide’ for Groups and Branches
- ‘Living with Boxes’ – supported by the Nick Smith Foundation
- Designing and commissioning of an evaluation tool to assess impact and progress
- Partnership development with Barnardo’s and Hope Support Services
- Therapeutic needs based on hospice offer
- Further development of Association educational resources and digital platforms
Young people aged 11 to 18

Find support below if you’re aged 11-18 and you’re close to someone with motor neurone disease (MND). You’re not alone - we’re here to help.
Hello and welcome to our activity hub.

Come and explore our games, activities and info pages.
Why are things changing?

Stories about families and MND
Funding

- Lightfund – 10K towards memory making days and development of the evaluation tool
- Children in Need grant – potential to work in partnership with national children’s charity Barnardo’s
- Nick Smith Foundation – Living with boxes
- Local fundraising
- Small scale funding streams
Activities
- Needs analysis to inform strategy
- Memory days
- Living with boxes
- Partnership working (Hope/Barnardo’s)
- Therapeutic support via hospices

Outcomes
- Increased access to specialist services
- Increased understanding of situation
- Increased peer support

Outcomes
- Increased emotional resilience through coping mechanisms
- Increased self esteem and happiness

Outcomes
- CYP are empowered to fulfil their potential
- Minimising the long term negative impact of loss for CYP and society

Impact
- Improved wellbeing for pwMND, CYP and wider family
- Improved life chances for CYP affected by MND
Our future

Milton Keynes CYP event April 2019

Our support makes a difference now.
In years to come, that support may be returned.
“My greatest fear is not that I am dying, it is the welfare of my boys and how my family will cope.”