

SUPPORTING YOUNG PEOPLE AFTER MENINGITIS AND MENINGOCOCCAL SEPTICAEMIA

BECKY HARTWELL AND JANE BLEWITT



BACKGROUND

Meningitis Now's extensive experience of supporting people, together with more specific research activity, provided valuable insight into the impact meningitis and meningococcal septicaemia can have on teenagers and young people. In addition to the physical impact of the disease, young people can experience anxiety and isolation that affect their education, employment and social lives (1-3).

Believe & Achieve, a five year individualised programme of support and activities for young people aged 14-25 years affected by meningitis and meningococcal septicaemia, was developed to meet this need and launched in March 2018.

AIMS

Believe and Achieve aims to help these young people review where they are in life, set and achieve goals, overcome challenges, make new friends, learn new skills, celebrate successes and develop the confidence to believe in themselves.

The Outcomes StarTM (4), a family of evidence-based tools for measuring and supporting change, is used to help young people identify their own needs and priorities in life, education and work.

OUTCOMES

- 1. Young people will gain new skills and opportunities to better equip them for education, employment and a successful future.
- 2. Young people will become more emotionally resilient and will face the future with confidence and optimism.
- 3. Young people will create a dynamic community of support, inspiring each other to lead more healthy, active and fulfilled lives.

THE FIRST 18 MONTHS

1. SKILLS AND OPPORTUNITIES

Workshops, attended by 93 participants, have included:

- Coping with change and dealing with stress
- Cooking and budgeting
- Health and fitness
- Social media skills
- Photography and editing

2. EMOTIONAL RESILIENCE

- Coaching and mentoring have improved communication skills and the ability to interact with others
- Counselling has improved coping strategies and emotional resilience

3. DYNAMIC COMMUNITY

- Residential weekends have enabled 22 young people to meet each other and undertake challenging activities together resulting in improved individual confidence and inspiration to face new challenges
- A dynamic online community enables individuals to share stories, news and advice

"I had the best day! I overcame so many fears and completed every single task. It was tricky sometimes and I was shaking like a leaf"

"As well as talking, I felt able to deal with my feelings as we went along. It's made me feel more positive and given me a different outlook on dealing with my problems"



FUTURE PLANS

Over 100 young people have accessed the programme through events, activities, one to one support or online information.

Evaluation of the first 18 months has identified the overall benefit of the programme, with young people continuing to guide its development and improvement Peer mentoring will be expanded, and following feedback from the 22 young people who accessed counselling, the need for ongoing emotional support will be addressed. Future planned activities include a creative day, social events in the north of England, Belfast and Edinburgh and residential weekends.

An outcomes framework is being developed to enable robust evaluation of the programme. This will guide continuing development and improvement, and ensure that young people affected by meningitis and meningococcal septicaemia continue to be supported.

BELIEVE

FUNDING

Believe & Achieve is funded for five years by the National Lottery Community Fund. Additional funding from BBC Children in Need, St James's Place Charitable Foundation, The Gannochy Trust and GSK.



REFERENCES

- (1) Viner RM, Booy R, Johnson H, et al. Outcomes of invasive meningococcal serogroup B disease in children and adolescents (MOSAIC): a case-control study. Lancet Neurol. 2012 Sep;11(9):774-83
- (2) Meningitis Now Adolescents and Young People Survey. Picker Institute Europe. 2014
- (3) Meningitis and Me. A survey of over 1100 people affected by meningitis, commissioned by Meningitis Now in partnership with Alterline. 2015
- (4) The Outcomes Star Tm. http://www.outcomesstar.org.uk/