‘MIND The Gap’

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NPF Project 2019/2020 : ‘MIND The Gap’

For many people the ‘what comes next’ is the hardest part and, for Neuroendocrine Cancer patients, living with uncertainty is a consistent and persistent challenge. The reality of cancer long term can be an anxiety ridden place, and we have to help patients carry, not only the physical but also the psychological burden of disease.

- To raise awareness of, and ‘fill the gap’ between hospital care and home regarding the day-to-day psychological and emotional burden of living with Neuroendocrine Cancer
- To support Neuroendocrine Cancer patients through their particular cancer experience
- To publish data from vulnerable patient population
- To provide recommendations to enable relevant and useful support
- To set up ‘Living with NC’ training sessions (in blocks of 6)- many exist for general cancer survivors but nothing specific for our community
- To raise funds to keep providing specialist psychotherapy services via NPF
- To provide further online resources, leaflets and training opportunities (for other counsellors/psychologists)
NPF Counselling Service

Established in July 2017 for patients and family members/supporters

In first 12 months of operation provided 184 sessions to 25 individuals (average no. of sessions 7.4)

Specialised approach combining aspects of psychodynamic, CBT, Mindfulness and ACT

Work in collaboration with specialist nurses/GP’s to help provide joined up care for more vulnerable patients

Nb AMEND Counselling Service (est.2014) - for genetic NETS and related conditions
Key presenting and emerging issues

* Correlates with ‘Living with a Rare Condition : the effect on Mental Health)’ Report: Genetic Alliance (2018) that 36% of patients and 19% carers living with a rare condition have experience suicidal thoughts
‘I’d been living with my NET for 5 years. I’m so embarrassed that it seems to be getting harder, not easier, even though I’m really quite well. Friends forget I’ve got it, and I feel very isolated.

I’ve had some new symptoms lately and I don’t know if its my age or the NET.
I’m angry and tearful all the time, I’ve started having panic attacks and not sleeping.

I’m really frightened’. Marjorie (55)

‘I’ve had enough of going from pillar to post, and feeling exhausted. My NET’S not cancer yet, so my boss is really unsupportive with all the time I have to have off. I’ve got a young baby and my partner’s just said she wants to split up. I keep thinking maybe it would be better if I was dead.

I did think about just driving into a wall on my way home last week’. Nick (31)
‘It’s cancer Jim, but not as we know it’; particular challenges for NET patients

- ‘Cure’ vs ‘palliative care’ model of cancer doesn’t ‘work’
- No linear pathway – eg typical treatment & recovery/decline route
- High levels of unpredictability and uncertainty over time
- Are symptoms ‘psychologically’ or ‘physiologically’ driven?
- Logistically burdensome
- Being the ‘patient expert’
- Being ‘rare’
- Familial impact (eg MEN etc)
Self-efficacy and dealing with emotions

Performance Outcomes

“Positive and negative experiences can influence the ability of an individual to perform a given task. If one has performed well at a task previously, he or she is more likely to feel competent and perform well at a similarly associated task” (Bandura, 1977).

Vicarious Experiences

“People can develop high or low self-efficacy vicariously through other people’s performances. A person can watch another perform and then compare their own competence with the other individual’s competence” (Bandura, 1977).

Self-Efficacy

“Self-efficacy is influenced by encouragement and discouragement pertaining to an individual’s performance or ability to perform” (Presner, 2010).

Verbal Persuasion

“People experience researchers from their body and how they perceive this emotional arousal influences their beliefs of efficacy” (Bandura, 1977).

Physiological Feedback

“People experience researchers from their body and how they perceive this emotional arousal influences their beliefs of efficacy” (Bandura, 1977).

Determining Efficacy Judgments

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Psychological flexibility / Resilience

1. Allowing movement between the condition ‘looming large’ and ‘receding’
2. Accepting the unpredictability of symptoms day-to-day
3. Living with uncertainty and loss
4. Accepting the impact on wider life aspirations
5. Tolerating the ‘unknown’

“It’s like walking a tightrope you can’t step off, . . . I can’t relax too much into ‘feeling ok’, as then I’ve got side-swiped by something and am back to square 1, . . . but equally you can’t be preoccupied by it all the time ‘cos that drives you mad. Trying to find the balance is really exhausting.” Paul (51)
Managing difficult emotions

- BREATHE – and LISTEN
- ASK! ‘What can I do?’, ‘What do I need?’ ‘Is this realistic / logical?’, ‘What has helped before?’
- ‘What would you like me to do?’, ‘How would you like me to help?’
- Looking after yourselves – and each other (ie put on your own ‘oxygen mask’ first)
Talk with someone you trust

• ‘It wasn’t until the nurse took me aside and said she knew of other people who struggled like me after this op that I broke down. Then I felt I could start facing it, and I wasn’t going mad. I still feel really tired (although according to my ‘bloods’, I ‘should be fine’) but I am managing better. She helped me talk to my consultant too. (Lisa, 38)

• ‘You know, thinking about it, she didn’t say much, she just listened . . .just . . .I say that like it was something small, but it wasn’t . . .it was everything – no judgement, no immediate attempts to ‘fix it’, no advice or recommendation . . .she listened and I felt heard . . .’ (Kate, 54)

• I’m so tired of living with this, always feeling unwell, dreading injections and tests. I was beginning to feel I should just opt out. I couldn’t say that to anyone, but the nurse asked how I was managing ‘in myself’ and I told her. She really listened and took me seriously, she didn’t just fob me off.’ (Brent, 60)
Contact details

- NPF Counselling Service: Email: counselling@netpatientfoundation.org

- AMEND Counselling Service: https://www.amend.org.uk/patients/support/counselling-service/

- Kym Winter (Psychotherapist) kym@kymwintertherapy.co.uk 07538 555208

Thank You