Addressing Neuroendocrine Tumour Related Emotional Issues

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Background: Patients diagnosed with a NET have many problems that they face at that time and in the months and years after diagnosis. Some of these issues are the same as those faced by anyone with a cancer diagnosis. Some are more specific to patients with NETs.

Methods: In depth interviews with patients in the UK, USA and Canada reveal these issues and as patients with NETs may survive for many years, issues must be addressed.

Results: Immediate response to diagnosis may be anger, fear or a feeling of isolation. Questions arise, “am I going to die”, “how long have I got” “have I been told the complete truth?” Patients are greatly concerned about best treatment options and where to obtain treatments.

Issues surrounding partners, family and friends may be overwhelming. “How will they respond to the news, will they step back, will they be there for me or shall I be alone through the time ahead?” Money issues include “can I keep my job, the mortgage, will I see my kids through their education, if I don’t survive will my family cope financially?”

Embarrassing symptoms, pain, diet, body image and sexual issues are important too.
Problems are confounded by confusion surrounding diagnostic tests, and the major ongoing issue surrounding treatment options. As options have increased, the best personal option has become confuses patients. As more informed patients are increasingly common they become the advocate for their own treatment pathway. Information gleaned from the internet may be far from helpful.

Conclusion: Patients need support to cope with the emotional issues and worries that they have relating to their diagnosis.