OPEN CONVERSATIONS:

NEUROENDOCRINE CANCER & MENTAL HEALTH

REPORT

raremInds
Mental Health for the Rare Disease Community

Neuroendocrine Cancer UK
(Formerly NET Patient Foundation)

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With Thanks to **David Phipps** and **Rebecca Hargreaves** (NCUK Counsellors) for their input and comments throughout the preparation of this Report.

Special thanks

This report is illustrated with anonymised quotes primarily from those who have used the NCUK Counselling and Psychotherapy Service, and from the NCUK MIND the Gap Survey (2018). We are extremely grateful to all NCUK patients and family members who have given their kind permission for their experiences to be shared in this report. This Report is dedicated to them.

FORWARD

I am the Chief Executive Officer (CEO) of the Neuroendocrine Cancer UK (NCUK) charity, which was formerly known as NET Patient Foundation. I co-founded the charity in 2006 alongside our current chair Peter Gwilliam and two patients with neuroendocrine cancer, Andy Geach and Kathy Kalamis. I am the driving force behind our charity and ensure that all staff, collaborators, and contractors focus on the purpose of the NCUK as part of everything they do.

I have dedicated the past twenty years of my career to improving the care and outcomes for patients with neuroendocrine cancer. As the first dedicated neuroendocrine cancer Clinical Nurse Specialist (CNS) in the UK, and setting up the first UK-wide charity, I have experienced extensive challenges, alongside a significant sense of achievement. My passion is to see the following eight strategic priorities be achieved in the field of neuroendocrine cancer:

1. Protecting the UK's world class neuroendocrine cancer services
2. Improving the impact and outcomes for patients who follow a less common disease pathway with the development of a dedicated neuroendocrine cancer patient care pathway
3. Establishing and delivering educational initiatives that provide relevant information on the burden of a neuroendocrine cancer diagnosis
4. Promoting the need for a collaborative environment to deliver a high-quality service for patients, both in the acute and community setting
5. Providing standardised, useful, and accurate patient and public information
6. Significantly advancing research in, and awareness of, neuroendocrine cancers
7. Ensuring all patients see the right person at the right time in the right place
8. Promoting equity - the right of all diagnosed with cancer.

This report focuses on providing a greater understanding of the psychosocial and emotional impact of living with neuroendocrine cancer and makes recommendations to all healthcare professionals who work with these patients to provide them with the best possible understanding and care to improve their daily lives.

CATHERINE BOUVIER
CEO and Co-Founder, NCUK

Neuroendocrine Cancer UK
(Formerly NET Patient Foundation)

Establishing a new specialist Counselling and Psychotherapy Service with NCUK in 2017 was borne of two key factors. Firstly, the increasing awareness by NCUK and the wider neuroendocrine community of the significant psychosocial challenges faced by patients and their family members in both being diagnosed, and living with this neuroendocrine cancer over time. Secondly, the difficulties faced by patients and their family members in accessing counselling and psychotherapy support that met their needs, and the case for a specialist service that understood neuroendocrine cancer seemed clear. Drawing on the experience of providing specialist telephone and online counselling and psychotherapy for the Association for Multiple Endocrine Neoplasia Disorders since 2013, the new online service offered a breadth of access and expertise that would not be possible via a face-to-face service.

Our belief at NCUK CaPs is also that a 'little can go a long way' on the part of medical healthcare professionals in relation to acknowledging and addressing mental health needs. By validating and acknowledging to patients and family members the complex biopsychosocial impact of a neuroendocrine cancer diagnosis, this in itself has therapeutic value. Mental health support is not just sign-posting to psychology services, counsellors or therapists. It includes the preventative-supportive function of good care-coordination, 'ordinary, kind enquiry' as to how a patient is coping, the support and information provided by patient advocacy organisations , the camaraderie of peer support groups, and the range of holistic care provided by both national and local generic cancer support or mental health services .

The right intervention with the right person at the right time can be truly transformative and potentially lifesaving. Support for mental health and wellbeing has arguably never been more important, particularly given the impact of the COVID-19 pandemic and the additional uncertainties and pressures of the last few years. This holds true not just for patients and families facing disruptions to their care, but also for the healthcare professionals treating and supporting them. Neuroendocrine patient care can be medically and emotionally challenging at the best of times. The additional strain placed on the mental health of healthcare professionals during the last few years (particularly here in the UK) as a result of a number of factors, and the need for additional individual and systemic support for professionals mental health , should also be acknowledged.

This report is not the product of a formal research study, but is intended to share some of our observations and findings from the last 4.5 years. We have provided a number of simple recommendations for healthcare professionals and also a practical, shareable resource (Appendix B) for use in clinics, or by patient advocacy groups.

At raremindsCIC , we firmly believe that physical and mental health are fundamentally entwined, and that mental health is everybody's responsibility. In keeping with its' title of 'Open Conversations', we hope that this report will encourage both patients and healthcare professionals to 'open and initiate' conversations about mental health, and keep that conversation 'open and ongoing' throughout the experience of living with this challenging cancer.

KYM WINTER
Rareminds CIC, Director

raremindsMental Health for the Rare Disease Community

INTRODUCTION

> *"People with a rare or less common cancer are disadvantaged at every step of their journey with cancer. From the speed of diagnosis through to treatment and research, people with rare and less common cancers often get a second-class service and a poor deal. It is time to level the playing field – by ensuring that people are treated equally, that they get the specialist treatment they need and that they are properly supported to live their lives as fully as possible. It is time for policy makers, health professionals and commissioners to acknowledge the differences in patient experience and to take positive and meaningful steps to address them."*
>
> **(CANCER52, 2015, P.3)**

Neuroendocrine Neoplasms (NENs) are rare/uncommon cancers that originate in the neuroendocrine cells - specialised cells that are responsible for releasing hormones into the bloodstream. Due to the location of neuroendocrine cells, these cancers can develop in many different organs in the body. Historically referred to as Neuroendocrine - or even Carcinoid - Tumours (NETs) - a recent shift in terminology to use the more accurate acronym NEN (Neuroendocrine Neoplasm) has been promoted. This term NEN encompasses both Neuroendocrine Tumours (NET) and Neuroendocrine Carcinomas (NEC), offering improved delineation between these 2 key categories of neuroendocrine cancer (based on cell appearance and behaviour/growth rate). NENs are often considered to be unusual cancers not only due to their perceived rarity, but also because of the variability in appearance and growth rate.

We use the terms neuroendocrine cancer in this report. Where a source is cited which uses the term NEN or NET, we have kept the original terminology.

While from a healthcare professional (HCP) perspective, the use of the term neuroendocrine cancer can provide clarity as to the nature of disease, the word 'cancer' can and does instil fear and anxiety in many patients. This fear is predominantly based on the fact that patients see cancer as a vicious, unpredictable, and indestructible enemy that is associated with few strategies to keep it under control; as a disease with both personal and social implications; and as synonymous with death (Robb et al., 2014; Vrinten et al., 2017). Conversely, for other patients, including the word 'cancer' in their diagnosis offers confirmation and validates the seriousness and potential impact of their condition. One of the most difficult ethical dilemmas for HCPs working in oncology is whether, when, how, and how much to tell a patient about their diagnosis and prognosis (Kazdaglis et al., 2010). Testament to this is the fact that some HCPs will not have told their patients that they have a cancer - in this scenario, only when their disease progresses might the word cancer be used.

Suspicion or initial detection of neuroendocrine cancer varies. It may occur incidentally - where the individual may have no symptoms but has undergone health screening or investigation for something else; and this screening/investigation may lead to diagnosis. Alternatively, it may occur as a result of seeking medical advice about experienced symptoms. The absence or presence of symptoms can depend on a number of factors, including where the primary site is and/or the presence of secondary disease, growth rate (grade), and functionality. Functionality refers to whether the cancerous neuroendocrine cells have maintained usual functionality, which is to produce enough hormones (or similar substances) to keep the body working normally. About 40% of those with a neuroendocrine cancer may experience abnormal functionality - where excess secretion of hormones occurs, leading to health issues (Cancer.Net, 2021).

Symptoms may be masked by or mimic symptoms of more common conditions such as IBS, asthma, menopause or even anxiety, which can lead to delays in diagnosis or even misdiagnosis. The presence of pre-existing health problems may also contribute to challenges in accurately identifying neuroendocrine cancer, as symptoms may be attributed to these rather than a flag that something else may be occurring. In addition, 20-25% of those with neuroendocrine cancer may be told that their symptoms are due to psychological issues - that it is ‘all in their mind’ (Basuroy, Bouvier, Ramage, Sissons, & Srirajaskanthan, 2018).

The psychological burden of cancer is well-established, but less is known about the psychological impact of an uncommon cancer like neuroendocrine cancer. In 2017, a global patient-reported study (Singh et al., 2017) established that approximately two-thirds of patients feel that their neuroendocrine cancer affects their emotional health, with many patients living with a significant degree of emotional distress. Patients with rare conditions are known to experience anxiety and depression linked to the unpredictability of the disease and the lack of information available regarding the condition itself and its management (Bogart & Irvin, 2017; Feinberg et al., 2013). The variable and particular nature of neuroendocrine cancers means that this group face distinct challenges that are not addressed in existing psycho-social research on cancer (Plage et al., 2018).

Furthermore, the rare/uncommon nature of neuroendocrine cancer means that patients and carers can experience a range of difficulties or barriers in attempting to access psychological and emotional support. Reasons for this include fear of being misunderstood as a result of low disease awareness by both medical and mental health care professionals; anxiety about perpetuating an idea that their illness is ‘all in their mind’; reluctance to access hospice or cancer counselling services because of their association with end-of-life care or a treatment/survivorship model that is less applicable to neuroendocrine cancers. Long waiting lists, or not being offered a preferred counselling approach and difficulty in attending further appointments ‘in person’ when the number of medical appointments may already be high, can all inhibit access.

This report makes 3 simple recommendations that we hope can be integrated into ordinary, everyday practice by healthcare professionals and others who are responsible for treating and supporting neuroendocrine patients and their family members.

Recommendation 1:

Healthcare professionals to hold open and ongoing conversations about neuroendocrine cancer and mental health.

Recommendation 2:

Healthcare professionals should receive support and training to understand the psychosocial challenges and emotional impact of neuroendocrine cancer.

Recommendation 3:

Neuroendocrine patients and carers should have access to, and be able to be signposted, to specialised psychological support.

Living With Neuroendocrine Cancer

According to UK data (Cancer Research UK, n.d.; White et al., 2019) neuroendocrine cancers account for less than 2% of all cancers reported. The estimated incidence of neuroendocrine cancers (2017-2018) is 9.37:100,000 (White et al., 2019) - compared to 595.8: 100,000 all cancers (Cancer Research UK, n.d.). Over the last 2 decades, this incidence has risen exponentially - 371% compared to 116% increase seen across all cancers (White et al., 2021). This may, in part, be due to increased awareness of neuroendocrine cancers, improved general cancer screening programmes and uptake, and improved diagnostics.

The diverse distribution of neuroendocrine cells throughout the body means that neuroendocrine cancers can occur almost anywhere. The most common primary sites identified are the gastrointestinal tract including appendix, pancreas and lungs - other sites include the genitourinary tract, prostate, reproductive organs, breast, thymus, thyroid gland, adrenal glands and skin (Genus et al., 2019). The primary site of origin may not be identified by routine imaging or histopathology in 12–22% of cases (Berner et al., 2020).

Neuroendocrine cancers range from well-differentiated neuroendocrine tumours (NETs) to poorly differentiated carcinomas (NECs, small- and large-cell type) (Rindi et al., 2018). Although originally thought to be indolent tumours by comparison to adenocarcinomas, grade 3 (G3) NECs can be highly aggressive, resulting in widespread metastases and poor prognosis (Berner et al., 2020). The variation in clinical presentation and biology of neuroendocrine cancers cause significant challenges in diagnosis and management (Kunz et al., 2013) with these cancers often misdiagnosed, or diagnosis frequently delayed (Singh et al., 2017).

As mentioned, the presenting or clinical symptoms of neuroendocrine cancer are varied. This may be dependent on where the primary site is (the part of the body, tumour size and position), the absence/presence of secondary disease (metastases) and whether the tumours are functional or not. Neuroendocrine cells have the capability to release hormones or similar bioactive substances - when these cells become cancerous this ‘function’ either remains unchanged or alters - resulting in excess release of hormones or similar substances.

Therefore:

- A non-functional neuroendocrine cancer is where this capability is unchanged.
- A functional neuroendocrine cancer is where this capability has become corrupted and excess hormone or bioactive substances are released.

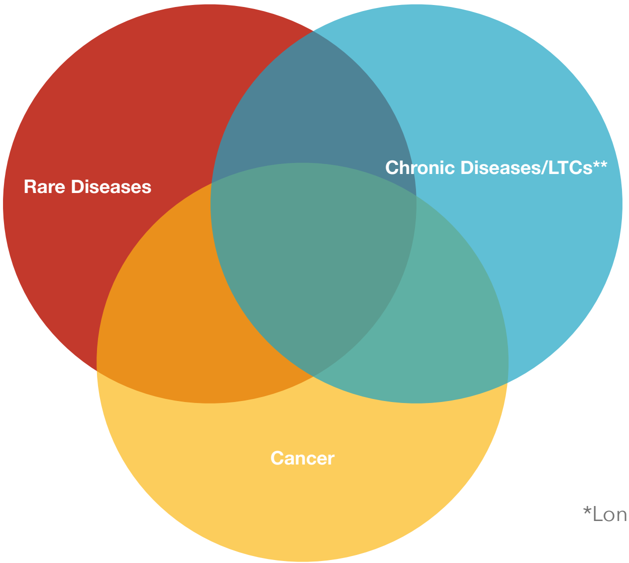
The majority of these cancers are non-functional, consequently the presentation may be incidental or related to mass effect or metastatic disease. Many patients, subsequently diagnosed often report a long duration of non-specific symptoms in the year prior to diagnosis - these may include intermittent pain, fatigue and/or changes in weight. Common symptoms described also include diarrhoea, pain, flushing, cough, wheeze, and tiredness/fatigue (Basuroy, Bouvier, Ramage, Sissons, & Srirajaskanthan, 2018; Basuroy, Bouvier, Ramage, Sissons, Kent, et al., 2018).

Quality of Life

Patient quality-of-life can be significantly affected by the type of neuroendocrine cancer, presence, variety, and severity of symptoms they experience, and the medical management of their disease (Bouvier & Jervis, 2021; White et al., 2020). Persistent daily physical symptoms can have a consequential impact on other aspects of the patient's life such as energy levels, ability to work/study, complete domestic chores, or care for other family members. Many patients with neuroendocrine cancer must make lifestyle changes, find working more challenging, and are burdened by subsequent financial strains (Singh et al., 2017). Approximately two-thirds of patients feel that their neuroendocrine cancer affects their emotional health, with many patients living with a significant degree of psychological distress (Singh et al., 2017). This distress can manifest in many ways including but not limited to, anxiety, depression, low mood, anger, and impaired tolerance of physical symptoms. Not only does neuroendocrine cancer impact on the patient's wellbeing, it also has a significant impact on their family, carers, and support network too.

Neuroendocrine Cancer: the Intersectionality of Rare Disease, Chronic Disease, and Cancer

Neuroendocrine cancer sits at the interface of rare/uncommon diseases, cancer, and chronic diseases. There is ample evidence across these domains of the psychosocial challenges of each. Consequently, psychosocial challenges faced by neuroendocrine cancer patients and carers are compounded and amplified, as a result of this intersectionality.



*Long-term conditions

The emotional impact of any cancer diagnosis is well-documented impacting quality of life, survival rates, and the experience of treatment physically and emotionally. A comprehensive review and meta-analysis of mental health and cancer indicated that approximately 35% of patients experienced depression, and a further 10% anxiety (Pitman et al., 2018). In cancers that secrete chemicals known to impact mood (such as functional neuroendocrine cancers), this proportion is likely to be higher. Harley et al. (2012) proposed the term chronic cancer to include patients newly diagnosed with advanced/metastatic disease, those under active treatment, or those receiving supportive or palliative care (but excluding patients in the end-of-life phase.) Many neuroendocrine cancer patients could be said to fall under this definition. Overall, worry and anxiety in those experiencing 'chronic cancer' is high (almost 75%), with uncertainty described as the most difficult aspect to cope with (Boele et al., 2019). This uncertainty is amplified in rare/uncommon cancers as "less information is available, awareness, knowledge and expertise is limited, and the type of cancer itself is complex, unpredictable and currently, often incurable." (Bouvier & Jervis, 2021, p. 256).

In common with many rare/uncommon disease patients, neuroendocrine cancer patients often face a lengthy diagnostic odyssey. Basuroy and colleagues found that the median time from first symptom to diagnosis for neuroendocrine cancer patients was 53.8 months (Basuroy, Bouvier, Ramage, Sissons, & Srirajaskanthan, 2018). 80% visited their GP on average 11 times before diagnosis, and 30% were diagnosed through A&E. Singh et al. (2017) found that 29% of patients waited over 5 years for a neuroendocrine cancer diagnosis. Regardless of whether neuroendocrine cancer is diagnosed incidentally, or after a long diagnostic odyssey, the experience of diagnosis is frequently described as traumatic to varying extents. Giesler et al. (2018) discuss the important question as to whether cancer diagnosis is a trauma for patients and doctors alike.

The Psychological Impact of Neuroendocrine Cancer: Consistent Themes

In Appendix A, we give a more detailed overview of the issues that are brought to the NCUK Counselling and Psychotherapy service (NCUK CaPs). However, we have identified seven over-arching themes that emerge consistently in our work with neuroendocrine cancer patient experience, and impact mental health and wellbeing for patients and caregivers alike.

1. Living With the Sword of Damocles [1]

A particular challenge of neuroendocrine cancer is how to adjust psychologically to living with a disease often described as 'treatable but not curable', and manage the emotional (and practical) burden of that fact over time. The optimal state may be for extended periods between scans when disease is stable, although this period can also bring its own psychological challenges with respect to warding off the fear of disease progression/return on a cyclical basis. For many neuroendocrine cancer patients and caregivers, living with chronic, background anxiety about their disease is part of the 'new normal.' **The psychological challenge is how to psychologically 'accommodate' this anxiety without being either unduly in its grip, nor in complete denial, since both extremes can be problematic.** Psychological flexibility is key to being able to continue to embrace life, despite this new awareness of mortality.

In Boele et al.'s (2019) study of chronic cancer patients, almost half of respondents (48.6%) reported trying not to think too much about their illness, with a high psychological burden of disease over time. Nevertheless, 48.8% attribute aches and pains to the cancer growing, and over one-third of patients reported often feeling anxious or worried (39.9%) and scared of dying (37.5%). Beesley et al., (2018) describe consequential needs for ongoing coordinated care, and high levels of supportive care needs.

The fact that neuroendocrine cancer impacts life in a multitude of ways seems indisputable. The Global NET Patient Survey recruited 1928 NETs patients from over 12 countries (Singh et al. 2017), and found that 60% believed that living with their disease had substantially negatively impacted their emotional health; 48% the emotional health of family/friends; negatively impacted relationships with family/friends and with spouse/partner (34% and 35% respectively); and over half reported changes in their attitude towards daily life (52%) and their social life (51%). Hallet et al.'s (2019) retrospective population-based observational cohort study of 2721 Patients also found 30-40% patients reported moderate-to-severe anxiety symptoms. It further found that factors such as tiredness, impaired wellbeing, and anxiety occurred not just at diagnosis, but up to 5 years later.

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[1] The Sword of Damocles refers to the challenge of living with awareness of impending death. However, it also refers to how to continue to take pleasure in life whilst tolerating the psychological tension of knowing it can end at any moment.

2. High Disease Burden

Singh et al. (2017) found 92% of patients reported making one or more lifestyle changes as a result of their diagnosis, all of which further describe 'disease burden' which encompasses: time spent on managing diet, time taken off work to attend appointments or reduction in working hours/commitments, and consequential financial impact. Given the age range of this population, neuroendocrine cancer patients and caregivers are often managing the emotional and logistical impact of neuroendocrine cancer alongside work or caring responsibilities, thus compounding problems of neuroendocrine cancer related fatigue. This can lead to both emotional and physical exhaustion. NCUK CaPs clients often describe 'appointment fatigue' in the first year of diagnosis when medical baselines, extent of disease, and initial treatments options are still being established. Adaptations to the impact of neuroendocrine cancer are highly personalised: what one patient can manage to accommodate and integrate into everyday life, another will find considerably more distressing and difficult.

For many patients, it can take time to establish what may be post-surgical, disease/symptom related fatigue or pain, what might be the 'new normal' in relation to management of overall impact , and how (and when) to make life decisions accordingly. This can also have profound implications for identity, which can in turn take time to work through psychologically. Some NCUK CaPs clients experienced their cancer diagnosis as a 'wake-up call' to make bigger life changes i.e., early retirement, part-time working, changing jobs or acting upon hitherto post-poned decisions around relationships or lifestyle.

3. Low Disease Awareness

Many neuroendocrine cancer patients 'look well' which can mean the severity of their disease (including its emotional impact and psychological burden) is much less apparent to friends, work colleagues, and family members. As a result, they may elicit less social support and sympathy than those with more common signifiers of illness or cancer such as mobility issues, or weight/hair loss. Plage et al. (2018) describe neuroendocrine cancer patients as being on the periphery of more familiar narratives and wider socio-cultural understandings about cancer. They include the psychological implications of this marginality which includes questioning by self and others about the legitimacy and credibility of neuroendocrine cancer as a 'proper cancer', and as deserving of being considered an illness. This marginality' also has a negative impact on emotional wellbeing, and features commonly in clients presenting at NCUK CaPs. A number of NCUK CaPs clients have had the veracity or severity of their diagnosis questioned by extended family members, employers, or HCPs with a clear inference of underlying assumptions about 'malingering' or 'over-dramatising'.

> “ *I feel that my NETs is viewed as an insignificant disease by the medical profession and others. I was told to go away and enjoy life. And feel that I should be grateful that my disease is not imminently life threatening.*
>
> (NCUK CaPs Patient)

Patients and caregivers are unlikely to meet or know of other neuroendocrine cancer patients without explicitly seeking them out through organisations such as NCUK. They are also unlikely to experience the supportive emotional impact of shared understanding about neuroendocrine cancer from within their own socio-familial networks (i.e.,in contrast to those experiencing more common cancers such as breast or prostate.) More generic cancer support organisations will also have limited encounters with neuroendocrine cancer patients/caregivers. The lack of readily available common understanding and shared lived experience is likely to further compound a sense of isolation which can also negatively impact emotional wellbeing.

> “ *The skirting around the ‘is it cancer or not’ issue was distressing. I didn’t see the oncologist until 5 months after my diagnosis by a general surgeon. I was not offered support by a specialist cancer support group. I was left feeling like a fraud.*
>
> (NCUK CaPs Patient)

Lack of disease awareness also contributes to the background anxiety inherent to living with neuroendocrine cancer when engaging with HCPs for ‘ordinary’ health issues. Anecdotally, patients and caregivers report instances of the diagnosis being questioned or minimised, being told they are fortunate to have a ‘good’ cancer, and of potentially life-threatening situations whereby HCPs have reduced or queried medications prescribed at unusual dosages to stabilise neuroendocrine cancer.

> “ *People saying you look well is a mixed blessing. I mean it’s nice on one hand, but when you really don’t feel great it’s pretty upsetting, and lonely. Someone in the Natter Group [a peer support group] says they always respond with ‘you should see my insides!*
>
> (Patient)

4. The Complex Physical-Emotional Interface of Neuroendocrine Cancer

A number of patients approaching NCUK CaPs are preoccupied with how to interpret their own low mood or anxiety (i.e., 'is it me or is it my hormones?') This question is especially acute for women diagnosed or living with neuroendocrine cancer and dealing with menopause, which many did not feel was taken into sufficient account by their care team. A high percentage of NCUK CaPs patients present with fatigue and/or pain which negatively impacts their mental health and wellbeing, although what percentage is related respectively to the mental or physical health impact of their cancer is often hard to ascertain with certainty. What is notable is that patients often report either their pain and fatigue improving, or they are 'experiencing it differently' following a course of counselling (NB more research in this area would be helpful, particularly in gastrointestinal neuroendocrine cancer patients given the complex mind-body-gut axis).

Of NCUK CaPs clients who disclosed taking anti-depressant medication, most had been prescribed via GPs. As anti-depressants usage for neuroendocrine cancer patients can be controversial (Izenberg-Grzeda et al 2020), many felt that fully considered choices about how to manage both their physical and mental health in conjunction (and / or anxieties in this regard) were not always well addressed by either their neuroendocrine cancer specialist, or their GP. For NCUK CaPs patients who were encouraged to cease anti-depressant usage on diagnosis, some expressed anxiety as to the ramifications for their emotional wellbeing at this vulnerable time and did not feel this was well understood by HCPs.

La Salvia et al., (2021) draws attention to the need for greater awareness of potential psychiatric symptoms in carcinoid syndrome due to hormone secretion, and suggests the routine use of the Hospital Anxiety and Depression Scale (HADS) to assess anxiety and depression symptoms. They also suggest liaison psychiatry may have a role to play in the management of the serotonin-producing types that can profoundly impact mood.

5. Managing Uncertainty

Neuroendocrine cancer involves numerous over-lapping uncertainties. For neuroendocrine cancer patients and carers (including HCPs), this extends across **macro uncertainties** around prognosis or disease progression, the unpredictability of treatment responses, and the variable day-to-day presence or absence of symptoms such as bowel issues, fatigue, or pain. It includes the cumulative impact of **micro uncertainties** such as when appointment dates will be received, whether a preferred doctor will be conducting an appointment, the timing of the arrival of a nurse giving injections, or availability and quality of 'remote' support between appointments. All have consequential impact on employment, psychological health and wellbeing, personal relationships, and quality of life. Emotional wellbeing relies upon the robustness and flexibility of coping strategies that can put in place to manage these uncertainties not just in the short-term, but over time.

> “ *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 all, 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.*
>
> (NCUK CaPs, Patient)

Patients face regular 'reminders' of disease presence because of surveillance scans, intrusive symptoms, or regular treatments such as somatostatin analogue injections. Many neuroendocrine cancer patients experience little true 'time off' their disease – or remission as such - that might also allow 'emotional respite'. Shifting psychological energy from more familiar cancer related narratives around 'fighting', to 'living with' neuroendocrine cancer, must eventually be negotiated for longer-term emotional wellbeing.

> “ *It's like walking a tightrope you can't get off. You can't relax too much into feeling ok, as then you get side-swiped by something and are back to square one. Equally you can't be preoccupied by it all the time as that just drives you crazy. Trying to find some sort of balance is exhausting.*
>
> (NCUK CaPs, Patient)

The psychological challenges of watch and wait should not be underestimated. The surveillance cycle can itself be emotionally challenging, involving 'ground-hog day' cycles of building anxiety (pre-scan), suspension (awaiting results), and relief. Long periods of relative wellness can also mean that patients and carers are less psychologically prepared for decline or progression when it does eventually occur.

NCUK CaPs clients who may have been stable for long periods commonly describe progression or recurrence as more distressing than (or equivalent to) initial diagnosis. Hallet et al. (2019) found that neuroendocrine patients suffer a high symptom burden at the end of life, drawing attention to the need for supportive, personalised, and holistic care at this time. This inevitably carries implications for mental health and wellbeing support provision.

6. The Quality of Relationship With Healthcare Providers

For patients presenting to NCUK CaPs, a good relationship with at least one HCP seems to have some protective mental health function. Trust in HCPs and mental health professionals can initially be low especially if the severity of the disease (or the experience of it) has been minimised or brought into question at some point, or when the diagnostic odyssey has also resulted in both delay and misdiagnosis. This can include reluctance to access mental health support should early symptoms have been misdiagnosed as 'all in their head.' 21% of relationship difficulties brought to NCUK CaPs were with healthcare providers. This included anxiety resulting from difficulty in obtaining a timely post-diagnostic referral to specialist neuroendocrine cancer care, 'personality clashes', not feeling listened to or taken seriously, difficulty in accessing doctor/CNS for advice between appointments, and 'story fatigue'[2]. By contrast, a 'good relationship' (as in feeling listened to, taken seriously, and being reliably available) with at least one neuroendocrine cancer HCP (doctor or CNS) was highly influential in ameliorating anxiety at diagnosis and beyond. For patients (or their partners) with an already established pre-existing history of poor encounters with health or social care professionals, neuroendocrine cancer can be a particularly anxiety-provoking diagnosis. Patients may also be reluctant to access generic cancer support services or palliative care. This is not just because of the associations with end of life, but because of the lingering feelings of 'not quite fitting in' to generic cancer services. Counsellors had concerns that this led in some instances to limiting access to more specialist care around for example, pain management.

The quality of the relationship with the HCP also had a consequential effect on a patient's emotional capacity to tolerate difficult tests or treatments, pre-surgical worries and post-surgical recovery, and fears for the future. Anxious preoccupation about their health overall (as opposed to just being an informed and engaged patient) was understandably more common in patients who had experienced poor care or delayed diagnosis. A poor in-patient experience (e.g. , surgery/other treatment) following a poor diagnostic experience was extremely psychologically and emotionally challenging, further compounding low trust and heightening overall anxiety. The capacity to contact their known specialist CNS or doctor for support or advice , and confidence in inter-department liaison between HCPs significantly reduced anxiety for both patients and partners when engaging in active treatment such as surgery, radioligand therapy etc.

> “ *I have been left to 'get on with it' after major surgery. The only contact with anyone after was my NET nurse, who is brilliant.*
>
> (Patient: MindTheGap Survey (2018)

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[2] The experience of many rare disease patients as a result of becoming their own 'patient expert'. Story fatigue results from the need to educate others specifically and generally about their condition due to more general low disease awareness. It places a burden of responsibility upon the patient to be the 'holder of their own (medical) history' as the degree of understanding they may have of the condition surpassing that of the HCP. It can be empowering, but can also re-expose patients and care-givers to difficult or traumatic historical experiences. It also involves moving from a more 'dependant' relationship with HCPs to a more 'collaborative' approach to care. This dynamic relationship shift may be resisted by either party.

> *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.*
>
> (Patient: MIND The Gap Survey (2018))

7. Accessing Psychological Support: a Challenge for Patients, Caregivers and Healthcare Professionals

Although asking for mental health support is increasingly socially acceptable, stigma remains across the general population at the personal and socio-cultural level. Plage et al (2018) found that rare cancers in particular may inhibit help-seeking behaviour as a result of the questions that may exist around their severity and legitimacy . Boele et al. (2019) found that 25% of chronic cancer patients believed that Macmillan were just for end of life or palliative care. Both statistics suggest that a number of patients/carers who could benefit from earlier intervention do not access this. Over half of Boele et al.'s respondents had been given information about support services, but 56% said things would have to be 'really bad' before they sought out support.

Plage et al. (2018) also found that the absence of familiar cancer signifiers (e.g. looking unwell) that may ordinarily stimulate referral to, or enquiry about, emotional and social support needs, means these aspects are less frequently attended to by both HCPs and patients/caregivers. In those attending NCUK CaPs, this may result in a degree of distress or difficulty increasing in severity over time. Earlier engagement with counselling or other support services is likely to mean difficulties are less entrenched or complex as a result of the passage of time. Findings from Beesley et al. (2018) confirm a need for HCPs to foreground the emotional care needs of patients and families as part of routine care.

The NCUK MIND The Gap Survey (2018) asked patients and carers on the NCUK database about their experiences of mental health support at diagnosis and beyond. 84% had not been asked about how they felt emotionally about their diagnosis, 62% stated they were 'rarely' or 'never' asked about their emotional wellbeing at appointments, and 42% believed their emotional wellbeing was 'not at all' acknowledged by their healthcare team (Neuroendocrine Cancer UK (NCUK), 2018).

Some NCUK CaPs clients describe attempting to access statutory counselling (e.g. IAPT) either via self-referral or through their GP, only to be told they do not fit the referral criteria of the service. Others were offered interventions that did not meet their needs (e.g. computerised CBT programmes for generic anxiety, rather than counselling to address the emotional impact of diagnosis). 97% of clients approaching NCUK CaPs said it was 'very' or 'fairly' important that the counsellor had an understanding of neuroendocrine cancer, and 71% chose to use the service specifically because it is a specialist service. Private counselling is beyond the means of many, and few private practitioners are likely to have experience with the particularities of neuroendocrine cancer.

Over 80% of NCUK CaPs clients indicated they had not been offered counselling via their GP or hospital. It seems likely that patients/carers are not routinely made aware of specialist patient support organisations such as NCUK by HCPs. Over 70% of NCUK CaPs clients indicate finding the service via an internet search, or sign-posting from NCUK related activities/staff. Less than 20% indicated having been made aware of the service via a HCP.

Suicidal ideation: a theme to monitor

Although not a consistent theme across our population, suicidal ideation warrants inclusion. Large scale studies show an increase in both suicidal ideation and suicide risk after a general cancer diagnosis[1]) and amongst those with chronic illnesses[2]. A recent study of rare disease patients and carers indicated 36% of patients and 19% of carers had had suicidal thoughts[3]. There has been no large formal study on suicidality in neuroendocrine cancer patients, but NCUK CaPs note that in those that use their services , 13% disclosed suicidal ideation . Ideation did not seem to be associated with a particular period (e.g. first 6-12 months/ at decline etc) and may be exacerbated by many factors, including the hormone fluctuations associated with carcinoid syndrome etc. This has important implications for HCPs for integrating ongoing psychological support into routine care , particularly as both patients and carers may well be reluctant to disclose suicidal thoughts. A move from ideation to intent can be hard to predict even if screening is carried out for additional risk factors, and we are mindful too of the emotional impact of genetic inheritance i.e., in the multiple endocrine neoplasia syndromes. More research is needed in this area generally.

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[3] Spencer-Tansley, R., Meade, N., Ali, F. et al. Mental health care for rare disease in the UK BMC Health Serv Res 22, 648 (2022). https://doi.org/10.1186/s12913-022-08060-9

The NCUK Counselling and Psychotherapy Service: 5 Year Findings (see also Appendix A)

Appendix A (p26) contains further details about findings from the NCUK Online Counselling and Psychotherapy Service, including the key presenting and emerging issues brought to the Service.

Case Study : Gina

Gina * (52) approached for counselling having listened to a recorded talk via the NCUK website from a Patient Information Day on the psychological impact of neuroendocrine cancers. Gina had been diagnosed unexpectedly 14 months ago with a small bowel tumour and undergone surgery soon after. Several other small tumours in her liver were under surveillance. Despite assurances from the surgeon that she would be 'back to normal' after a few weeks, Gina was tearful, exhausted and struggling emotionally. Her diet remained restricted to just a few foods that she felt confident would not 'cause problems' and she described life as having become very insular. Unpredictable flatulence and the need to find a loo urgently had left Gina anxious and frightened about going out in case of 'accidents'. Her anxiety and low mood had been somewhat masked by the pandemic, but as restrictions lifted she was feeling increasingly tearful, panicky and under pressure to re-engage 'normally' with both her workplace, and normal life. Gina hated having monthly somatostatin injections, and was often both anxious and angry in the days preceding these. Her relationship with her husband was also under strain and Gina was tearful, frustrated and embarrassed about 'not coping very well generally.' Sessions initially explored Gina's anger and grief about the cancers 'intrusion' into both her body and her life, in part symbolised by the monthly injections which were so dreaded. Sessions went onto explore themes around identity, change, and control - both over her body, and mortality. The counsellor also gradually introduced practical and emotional coping strategies for managing potentially embarrassing situations should they occur. Gina was supported to seek a dietetic referral, and her CNS was instrumental in refining medication for managing her bowel. Gradually, Gina's mood began to improve and she began to feel more cautiously confident about the future. A phased re-engagement with the outside world started with short walks to a supportive friends house, and culminated with her contemplating a return to work on a part remote/part in person basis.

*For reasons of confidentiality, 'Gina' is a composite case with identifying features removed.

RECOMMENDATIONS

Mental health is everyone's responsibility. Greater integration of mental health care needs and assessment into routine patient and family care is essential for both neuroendocrine cancer patients and family members.

We make a number of recommendations in this regard

Recommendation 1: Healthcare Professionals To Hold Open and Ongoing Conversations About Neuroendocrine Cancer and Mental Health

- Be aware of the psychosocial impact and mental health challenges throughout the neuroendocrine cancer pathway, not just at diagnosis
- Healthcare professionals to enquire about and consider mental health needs as part of routine care e.g. asking, 'how are you feeling within yourself?'

Asking 'how are you feeling within yourself?' acknowledges and validates this aspect of living with neuroendocrine cancer. It demonstrates interest and preparedness to engage with this aspect of care, and facilitates patients disclosing difficulties should they arise. Some patient and carer anxieties may be sufficiently alleviated just by being given the opportunity to respond, but sensitive enquiry can also facilitate further signposting or monitoring as necessary.

NB: The use of assessment tools such as HADS have a role to play in the screening of patients in neuroendocrine cancer clinics for emotional distress. However, we believe that these should be used *in addition*, not as a substitute for, sensitive ongoing dialogue about mental health as part of routine care.

Recommendation 2: Healthcare Professionals Should Receive Support and Training To Understand the Challenges of Living With Neuroendocrine Cancer.

- HCPs should feel confident to open conversations about mental health, and equipped to handle conversations sensitively.
- The NCUK Academy provides a range of CPD resources to support healthcare professionals. NCUK CaPs provides informal consultancy and support to HCPs concerned about patients/carers.
- NCUK will continue to raise awareness of the needs of neuroendocrine cancer patients across primary, secondary, and tertiary care.

We appreciate that neuroendocrine cancer is a complex disease that often involves a wide range of HCPs. Not all will feel confident in opening difficult conversations or asking about mental health and wellbeing. Patients may present with high anxiety, anger and frustration, there may be limited treatment options, and disagreement or uncertainty within teams themselves. The additional pressures on services and individual staff members since COVID-19 pandemic must also be acknowledged. For HCPs to feel confident to open conversations about patient mental health, additional training and support needs must be addressed, and additional sign-posting and resources made available.

The allocation of a liaison mental healthcare professional (e.g. psychologist, psychotherapist/ counsellor) familiar with neuroendocrine cancer to MDTs as well as for direct patient referral, has considerable merit.

Both the **NCUK Academy** www.neuroendocrincecancer.org.uk /ncuk-academy-nurse-course and **Medics4Rare Diseases** www.m4rd.org provide free, online training for nurses and doctors respectively on diagnosing and supporting patients and families impacted by rare diseases.

Recommendation 3: Neuroendocrine patients and carers should have access and be routinely signposted to specialised psychological support.

- Early signposting to a range of support services including patient advocacy organisations and specialist psychological support services (see Appendix B) can facilitate psychological adjustment, provide ongoing support and prevent difficulties from escalating.
- The NICE Guideline Level 4 model (on page 21) can provide useful guidance for the support of neuroendocrine cancer patients.

> *“Without mental health there can be no true physical health”*
>
> (Brock, 1951, p. 3)

Recommended Model of Professional and Psychological Assessment and Support

Self help and informal support

LEVEL	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

Table 1: NICE Guideline Level 4 Model

LOOKING FORWARD: A SUMMARY

Mental Health Support *and* Intervention Must Be Both Proactive and Responsive

'One size does not fit all' with respect to supporting the mental health needs of neuroendocrine cancer patients and their family members, which will fluctuate over time. **Mental health support is best seen on a continuum which allows patients and carers to access different types or intensity of support at different times.** The NICE Level 4 Guideline on page 21 can also be used to inform and guide provision.

The mental health support of neuroendocrine cancer patients and families involves a range of provision:

- General routine, sensitive enquiry by HCPs into patient wellbeing, good care co-ordination, and help in navigating complex hospital systems, and greater integration of mental HCPs into MDTs. Support with care co-ordination or navigating services can also play a significant role in either ameliorating or exacerbating patient/ carer mental health.
- Sign-posting to patient organisations such as NCUK for supportive expertise and information resources, and that can also facilitate peer support (online and in-person). The latter have an important function in providing positive emotional support through the sharing of lived experience, and promoting 'agency.' (NB Peer-based interventions can be very effective and important in also creating an environment that makes health-related choices easier (Jones et al., 2018).
- Access to generic mental health and / or cancer related services such as Macmillan, and MIND.
- Access to specialist counselling/psychotherapy or psychology services, preferably with at least some awareness of the particular psychological challenges of this group of patients.

LIMITATIONS OF OUR REPORT

This Report is based upon, and informed significantly by, the experiences of those contacting NCUK CaPs, and responses to NCUK's Mind the Gap Survey (2018). As such, its scope is inevitably limited. This cohort are motivated and engaged to either comment on or access mental health support. Both the underlying nature of their difficulties and experiences cannot necessarily be generalised to the wider neuroendocrine cancer population. We also acknowledge the lack of an exhaustive literature review, and the subjective collation of data (see Appendix A) by each counsellor in the service.

CONCLUSION

The psychosocial challenges faced by neuroendocrine cancer patients and carers as compared to the 'common' cancer population are significantly compounded and amplified due to the intersection of neuroendocrine cancers across cancer, chronic conditions and rare conditions. With the incidence of neuroendocrine cancer increasing world-wide, it is crucial that the unique psychosocial and emotional challenges of living with neuroendocrine cancer are recognised and addressed as part of good practice and routine care. Mental health is everyone's responsibility, and access to a broad range of psychosocial support according to patient need and preference is indicated.

APPENDIX A:

NCUK Counselling and Psychotherapy service (CaPs): Summary Overview

Background

The service was set up in 2017 by NCUK to provide specialist Online Counselling and Psychotherapy to both patients and carers affected by neuroendocrine. There are 2 female counsellor/ psychotherapists and 1 male counsellor with specialist training in the psychosocial impact of a) rare conditions and b) neuroendocrine cancer. The aims of the service are to:

- provide 'ease of access' remote one-to-one counselling with qualified counsellors with specialist awareness of the impact of neuroendocrine cancer.
- provide an educative and consultative function to both NCUK and the wider medical/ psychological community by raising awareness of the psychosocial impact of being diagnosed with, and living with, neuroendocrine cancer.

Access

Clients must self-refer to the service, which is free at the point of access. For the majority of clients, being able to access a specialist counsellor with specific understanding of neuroendocrine cancer is cited as a significant factor in contacting the service. In recognition of the fact that neuroendocrine cancer has fluctuating impact over time, clients are encouraged to return at a later point if necessary after completing a series of sessions (when possible to the same counsellor for continuity). The reassurance of knowing the service is also available in the future also incorporates a 'protective' mental health element.

Model

The service works on a flexible 6-12 session model. Sessions may be weekly or at longer intervals according to both assessed psychological need and optimisation of resources over time, with clients undertaking an average of 7 sessions. The approach is integrative incorporating aspects of psychodynamic approaches , CBT based mindfulness and psychoeducation . Counsellors/ psychotherapists in the team are all experienced clinicians who have undertaken additional CPD in working with rare diseases provided by raremindsCIC https://www.rareminds.org (who now deliver NCUK CaPs) and in understanding neuroendocrine cancer. Clinical work is supervised by a senior psychotherapist.

Presenting issues are recorded by the counsellor following initial assessment, with up to a further 3 emerging issues recorded at the end of therapy (see chart 2). Counsellors also record prevalence of emotional themes and relationship focus (see chart 4).

In 2021, the CORE10 clinical measuring instrument was introduced. This is a standardised clinical monitoring tool used by many counselling and psychotherapy services to assess type and severity of distress. Clients are asked to securely electronically complete forms prior to sessions commencing, and on completion (see Table A) .

Population Demographics

N=221; 21% Male, 78 Female; 0% Other; 89% patients; 11% partners/other family members

Pie Chart 1: Neuroendocrine Cancer Diagnosis

NB this is self-reported by clients on presentation . It became apparent to counsellors during their work that some clients self-describe their 'primary cancer' as the one causing them the most difficulty or is the focus of treatment/concern, rather than necessarily the original tumour.

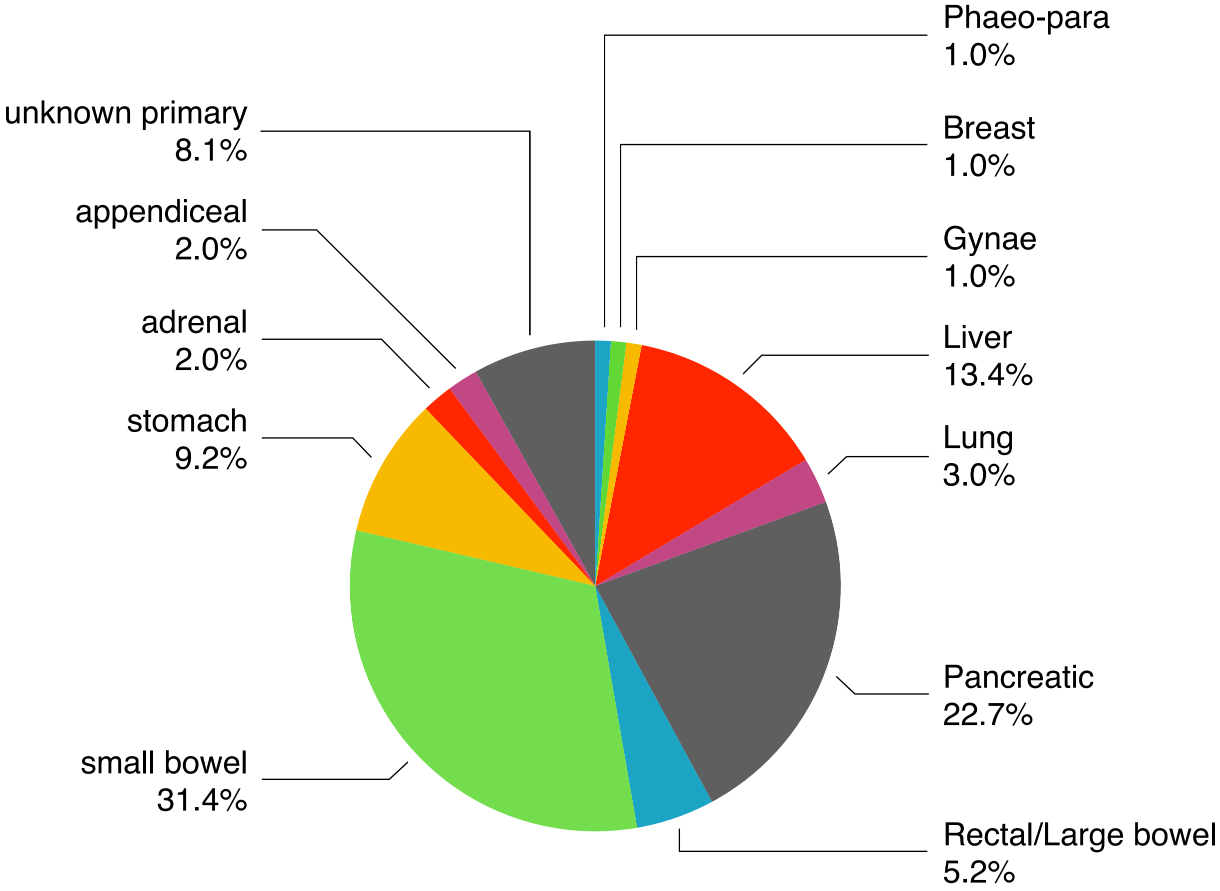


Chart 2: Presenting and emerging Issues

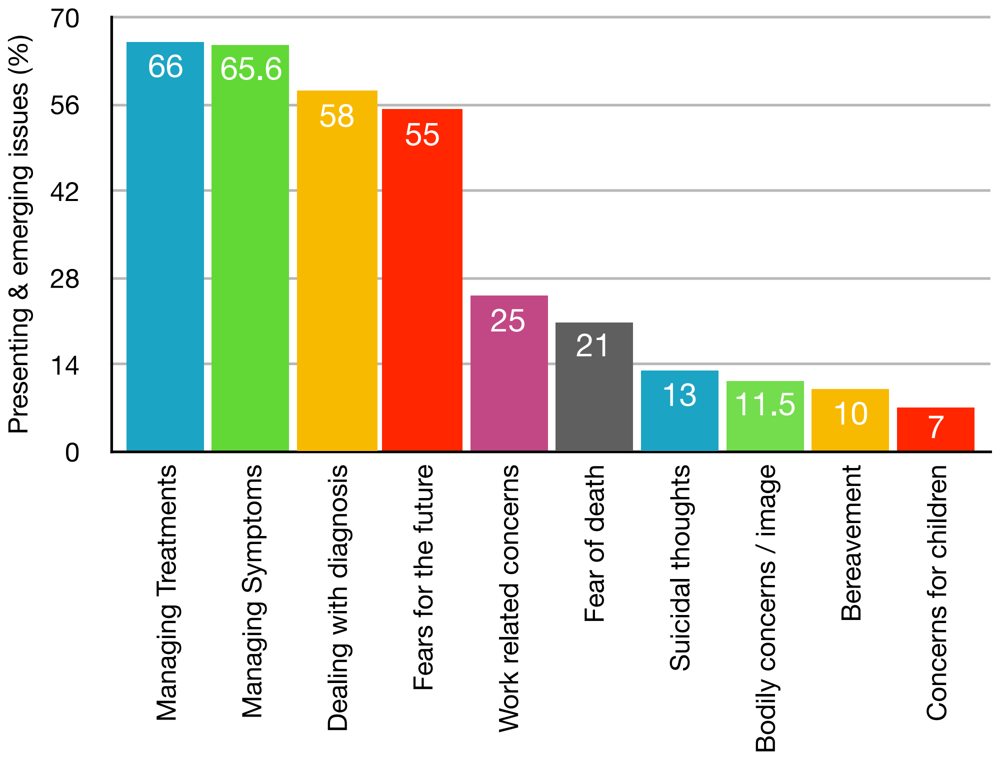


Chart 3: Focus of relationship-based anxiety or worry

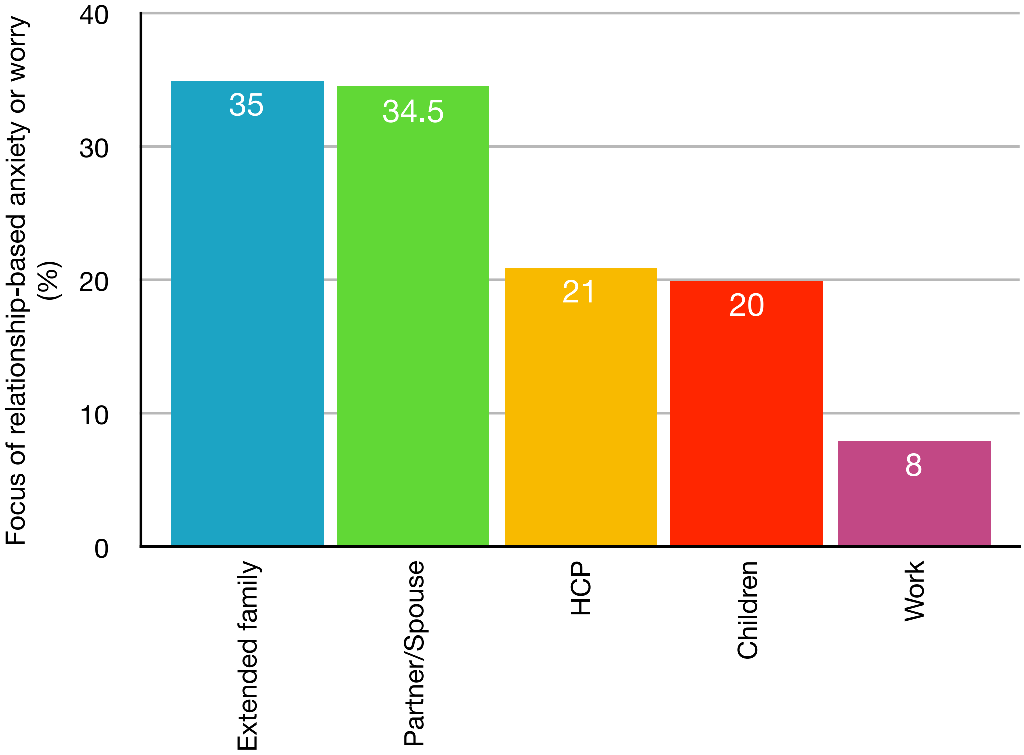


Chart 4: Emotional Themes

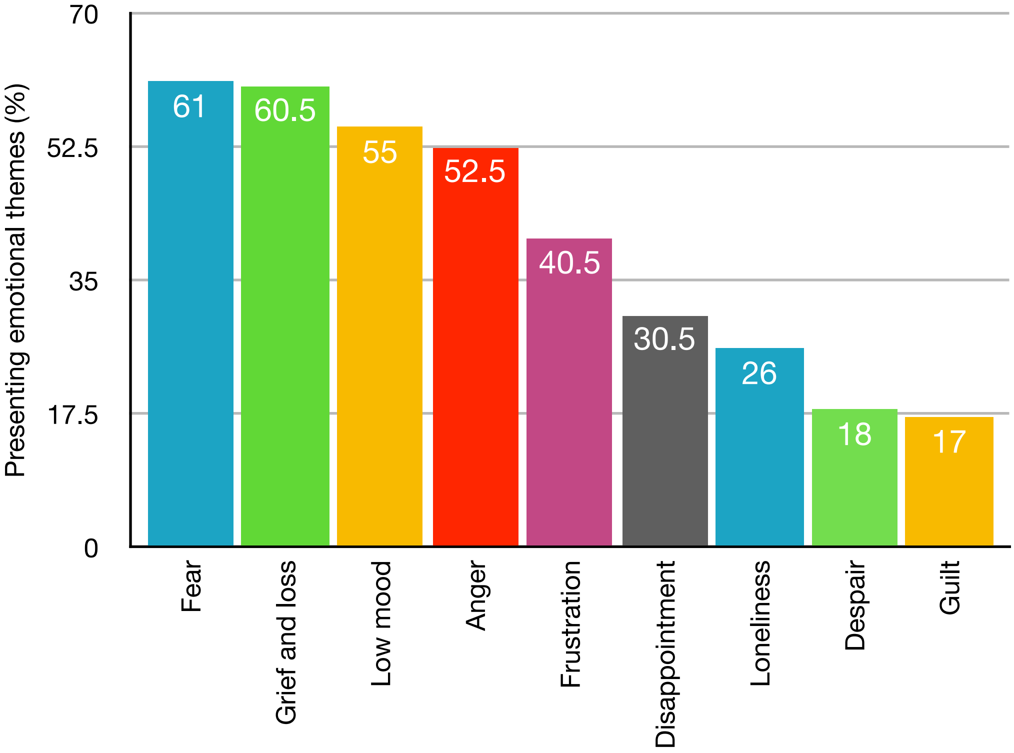


Chart 5: Focus of disease-based anxiety or worry

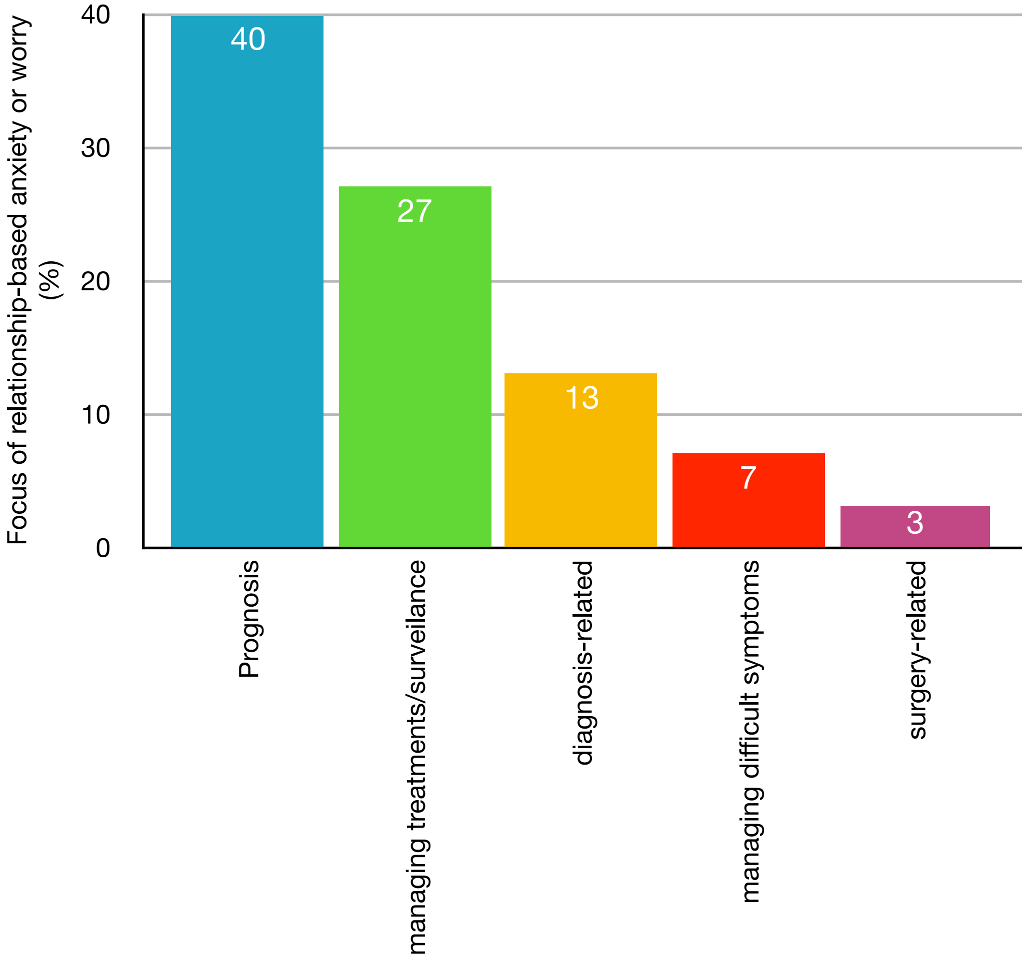
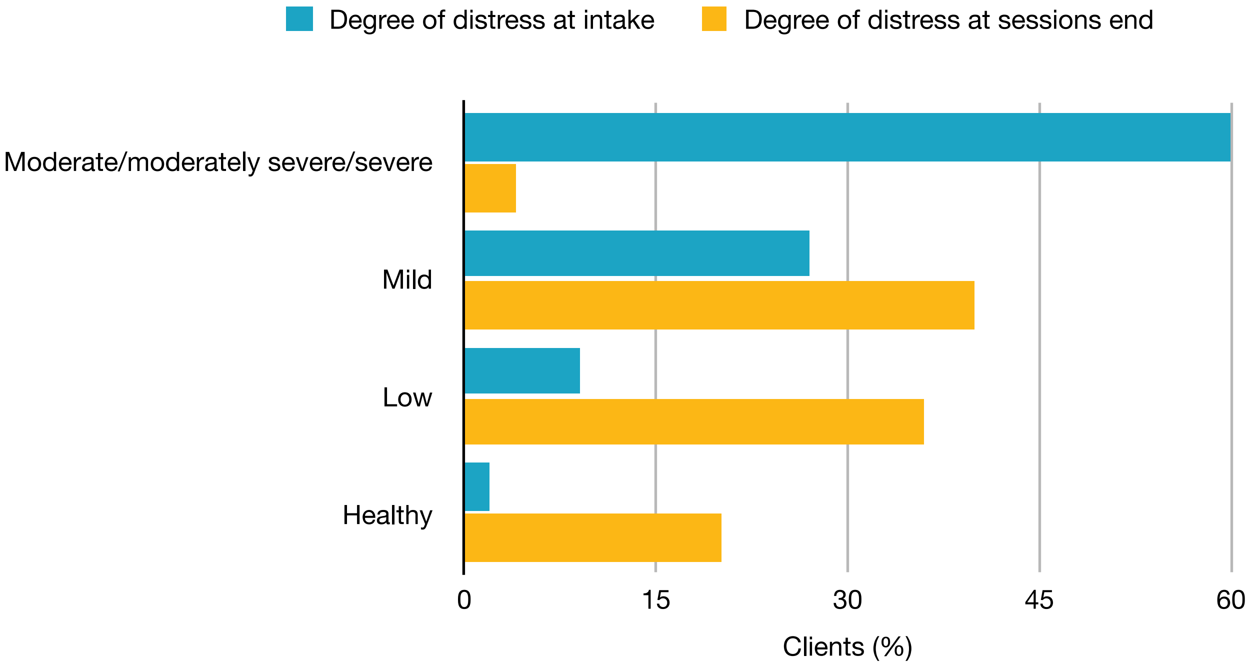


Table A: Degree and Severity of Distress using CORE 10. (N=71)



NB some clients would disclose indicators of a higher degree of distress (e.g. suicidal ideation, despair or low mood) than was apparent at commencement once a trusted relationship with the counsellor had been established.

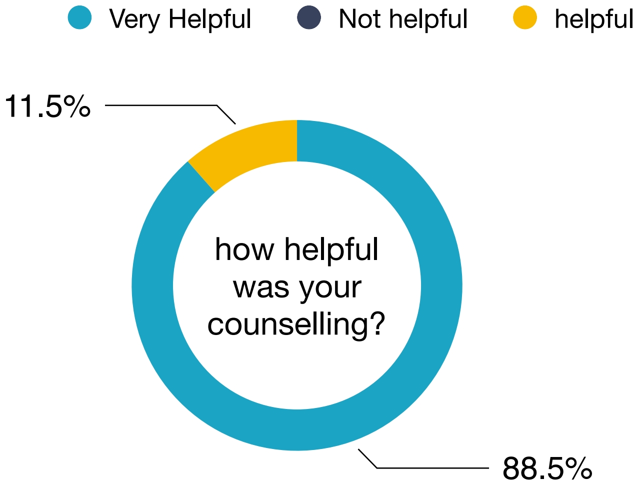
Service Satisfaction

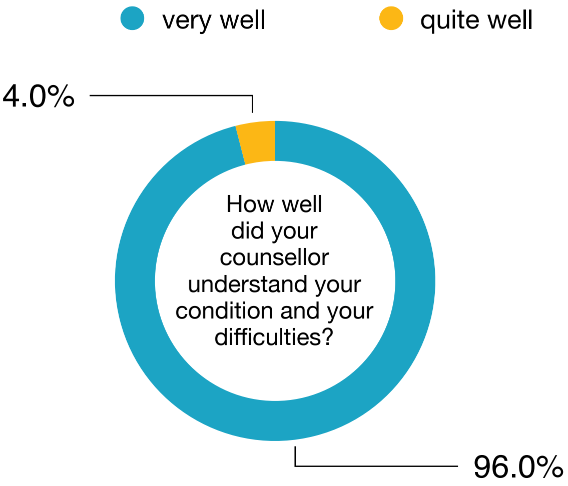
In addition to the reduction in severity of distress using CORE10 (see table A) , anonymised post-session feedback indicated satisfaction with the service is high.

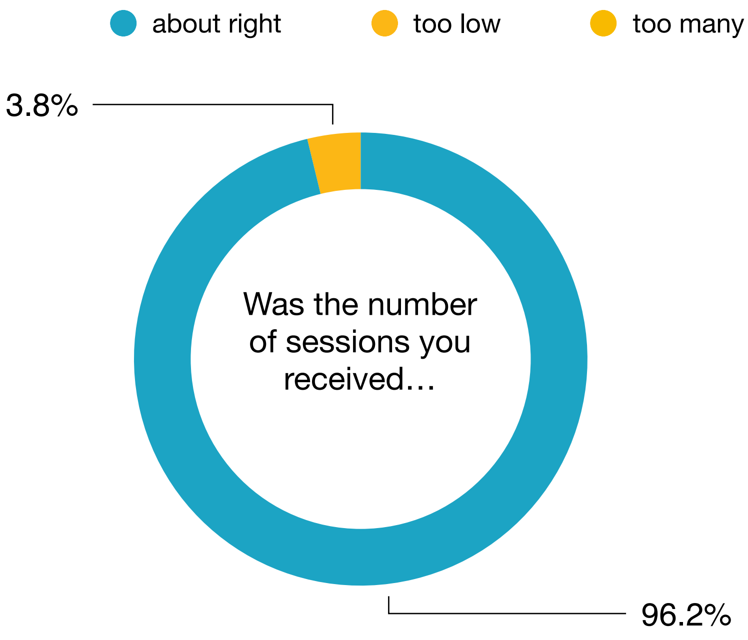
88.5 % describe the counselling as 'very helpful'; 11.5% as helpful; 0 % 'not helpful.'

96% said their counsellor understood their condition and difficulties 'very well'; 4% 'quite well'

97 % of clients said the number of sessions they receive is 'about right'; 3.8% 'too few'; 0% too many. (NB average number of sessions =7)







NB AVERAGE NUMBER SESSIONS = 7

> *I can’t thank [my counsellor] enough. I was really struggling with my husband’s diagnosis and we weren’t communicating well. My counsellor helped me find ways to open up frank, much needed dialogue and for us to understand how the other felt/was dealing with it.*

> *I honestly wouldn't be here if it wasn't for the counselling as I had no-one to turn to for help or support. I was under incredible pressure with the bullying from my employer who sacked me and was hounding me with threats of legal action. My counsellor saved me to be honest and I will be forever grateful to him and the NET organisation.*

> *I was really worried about accessing counselling. I had a really positive experience . [My counsellor] helped me think out loud and make sense of my thoughts. They also helped me realise that I was a normal person going through a hard time which made me feel less lonely. They knew about NETs and that was very important to me.*

Looking Forward

At the time of writing, the NCUK CaPs is over-subscribed and has had on two occasions in the last 2 years been obliged to close for referrals for a 3 month period in order to avoid management of a waiting list which would further stretch limited service resources. Despite its evident effectiveness, there are concerns about the service economic viability over the next few years, especially as demand is expected to continue to increase given the context of current economic and healthcare constraints in the UK.

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Resources for neuroendocrine patients and family members

When you, or a member of your family, are diagnosed with a cancer, it's not unusual to feel anxious, worried or frightened. If you have had a long journey to your diagnosis you might also feel angry or relieved. If it's come as surprise, you might feel shocked or in disbelief. You might not know what you feel, or just feel 'numb'. There is no right or wrong way to feel.

If you would find it helpful, or are struggling with anxiety, worry, or low mood, consider talking with someone you trust. This might be a friend, family member, employer, your GP, or a healthcare professional. The organisations listed below are here to support you whenever you are ready.

Neuroendocrine Cancer UK (NCUK) is a UK based and UK wide patient co-founded support organisation for anyone affected by neuroendocrine cancer (including carers and healthcare professionals). They provide:

- A Support Helpline with a specialist nurse and cancer support coordinator
- Peer Support Groups and Forums (on and offline)
- A specialist Online/Telephone Counselling Service
- Welfare grants
- Patient information , resources and events
- Training, education and grants for healthcare professionals

www.neuroendocrinecancer.org.uk

Association for Multiple Endocrine Disorders (AMEND) is a support organisation for UK based patients, carers, and professionals affected by (or involved in the care of) those diagnosed with rare genetic conditions that increase the risk of developing neuroendocrine cancer. They provide:

- Patient information, resources and events
- Peer Support Groups and Forums (on and offline)
- A specialist Online/Telephone Counselling Service
- Hardship Fund
- Young Peoples Groups
- Training, education and grants for healthcare professionals

www.amend.org.uk

Macmillan is the UK's largest cancer charity providing a range of cancer related information to people affected by cancer. They offer social, emotional, practical, and financial advice and support. They undertake research and lobby to improve cancer services and outcomes for patients and their families.

www.macmillan.org.uk

Carers UK provides advice, information and support for the partners, spouses and other family members of those living with a health condition. Looking after someone can be tough - Carers UK provides a support line, expert information and advice that's tailored to your situation, to support you in finding new ways to manage.

www.carersuk.org

Trekstock provides support services for those diagnosed with cancer in their 20s and 30s - and provides information, support, and advice on education, parenting, relationships, and sex/fertility issues.

www.trekstock.com

Maggie's is a charity providing free cancer support and information in centres across the UK and online. Amongst their services are free access to Support Specialists, Psychologists, and Benefits Advisors. They also provide a venue for many of NCUK's face-to-face Natter support groups **National advice line: 0300 123 1801**.

www.maggies.org

General Mental Health & Wellbeing

We have listed some general organisations below for both self-help and supported (professional) help.

Anxiety UK a charity providing support and information on managing anxiety, stress, anxiety-based depression and phobias.

www.anxietyuk.org.uk

Every Mind Matters an NHS website dedicated to mental health and emotional well-being. It provides useful self-help resources and advice on common issues such as anxiety, sleep problems, coping with worry and managing low mood. It also has information on how to access free NHS talking therapy.

www.nhs.uk/every-mind-matters

The British Association for Counselling and Psychotherapy provides a list of private counsellors and therapists by location and speciality (for example physical illness / cancer / relationships). Their website also provides information about counselling in general : including how to find a therapist and / or counselling approach that meets your needs. It has also has details of free and/or low cost services available both locally and nationally.

www.bacp.co.uk

Relate is a national organisation that provides information and support regarding relationship issues - past and present - for couples, and/or families. They provide a variety of resources for those whose relationship may be impacted by ill-health, including a cancer diagnosis - including finding a therapist.

www.relate.org.uk

rareminds a UK-based and UK wide non-profit organisation dedicated to supporting the emotional health and well-being of all of those affected by rare diseases, including rare and less common cancers. They also provide training and support for healthcare professionals, and patient advocacy group leaders.

www.rareminds.org

Emergency Support

If you or someone you know is feeling in crisis, over-whelmed, despairing or thinking about self-harm or suicide.

However bad things feel in the moment, you are not alone and help is available. During the day, you can try contacting your GP , or call 111, and let them know you are struggling. If you are at imminent risk, call 999 or go straight to A&E. The following organisations also provide excellent support:

Samaritans provide a free and confidential 24-hour listening service / crisis support - **text 116 123** or **email** jo@samaritans.org

www.samaritans.org

CALM (Campaign Against Living Miserably) (For Men) call 0800 585 858 (5pm-midnight) or visit their website

www.thecalmzone.net

Papyrus support for young people under 35 who are experiencing thoughts of suicide, as well as people concerned about someone else

0800 068 4141 - (9am-midnight)

Text SHOUT to 85258 - a free, confidential 24-hour text messaging support service

REMEMBER - YOU ARE NOT ALONE