

## **Mental Health and Well-Being Facing Neuroblastoma Survivors**

Cancer survivors of all ages experience normal challenges that may occur throughout the stages of life, but after a cancer diagnosis, they may experience *new* normal challenges. The experience of living with and living specifically through a neuroblastoma (NB) diagnosis and treatment can impact an individual's level of mental health and well-being compared with those without cancer experience. Mental health is impacted by biological factors, life experiences, and family history. Anxiety and depression fit under the umbrella of mental health, which is defined by our emotional, psychological, and social well-being. In addition to potential medical morbidities, neuroblastoma survivors are shown to be at increased risk for psychological problems, decreased emotional health, and impaired quality of life (Friedman & Henderson, 2018; Nathan, Ness et al, 2007).

In a large study of 5-year survivors of neuroblastoma diagnosed between 1970 and 1999 who are under 18 years old, results found that survivors had an increased prevalence of impairment in the domains of anxiety/depression, headstrong behavior, attention deficits, peer conflict/social withdrawal, and antisocial behavior when compared to siblings (Zheng, Krull et al 2018). Psychological impairment was associated with special education service usage and educational attainment less than college (Zheng, Krull et al 2018). Importantly, treatment intensity had no association with worse psychological outcomes in this cohort. Neuroblastoma survivors are at increased risk of psychological distress when compared to their siblings. However, there were no differences in these outcomes when comparing individuals with a history of neuroblastoma to other solid tumor survivors (Schultz, Ness et al 2007).

Because of the high burden of chronic diseases and the associations of these morbidities with reduced health-related quality of life (HRQOL) and social attainment, screening and interventions that provide opportunities to optimize health are important among neuroblastoma survivors (Wilson et al 2020).

### **How do we define Quality of Life (QOL)?**

Quality of life (QOL) is comprised of four interconnected areas: physical well-being (e.g., disease symptoms, treatment late effects), emotional well-being (e.g., coping, distress, anxiety, resilience), social well-being (e.g., social activities, relationships, family mental health), and functional well-being (e.g., school/academics, sports).

When comparing the QOL between parents and patients treated for Wilm's Tumor and Advanced NB, no significant differences on overall QOL was found, though NB was lower. When comparing specifically in patients with deficits in hearing and speech (due to platinum-based chemotherapy during treatment), a significant difference in QOL was found between the two groups. Overall, heterogeneity (differences) of

treatment for advanced NB makes conclusions difficult but morbidity is greater and more variable from early regimens with intensified treatments (Barr, et al., JCO, 2000).

On average, Wilm's tumor and NB survivors reported no decline on their physical QOL, but both groups scored significantly below norms on psychological QOL, reflecting decreased emotional health (Paul Nathan Pediatric Blood and Cancer, 2007).

**Mental health and well-being are crucial for development and resiliency.** Survivors and family members may benefit from monitoring and understanding emotional health through internalizing and externalizing behaviors.

Internalizing behaviors are not always easy to observe and are often directed inward; these behaviors may present as anxiety, depression, social withdrawal, irritability, difficulty concentrating, or negative self-talk. Externalizing behaviors are easily observable by others, and can present as aggression, disruption, or acting out. Survivors in particular may present as more withdrawn, increased social isolation, somatization, and decreased leadership ability, reduced self-esteem, and reduced intimacy with peers.

An entire family's well-being is essential. Parents can buffer the impact of stressful experiences on their children, with research demonstrating that parental coping and better family functioning can explain variance in the psychological adaptation of survivors. High levels of parental (especially maternal) distress and family dysfunction (i.e., lower cohesion, excessive control) are associated with increased behavioral, emotional, and social difficulties among children. What can we do as parents to protect ourselves and take care of NB survivors? Monitor and champion your own emotional health and well-being. Ask for help, seek parent support groups, peer-to-peer support, individual or couples therapy, keep a list of activities and things that are joyful or a "charge" (gives to energy, inspiration, motivation, peace), and know your own limits. Attend to your own physical health through wellness check-ups, exercise, diet, sleep, and meaningful activities.

### **Factors that can contribute to well-being and resilience**

A child's body and mind are always connected. Mental health can be negatively impacted by physical side effects or late effects of NB treatment. For example, hearing loss that occurs as a direct result of NB treatment can impact language and learning development. Consequently, this can impact aspects of emotional development including self-esteem, social relationships, feeling different than others, and anxiety.

While there is significant research on the potential neuropsychological, learning, and social-emotional issues for neuroblastoma survivors, there are many protective factors to consider and focus on to increase resiliency.

**Protective factors** are characteristics at the biological, psychological, family or community (including peers and culture) level that is associated with a lower likelihood of negative or problematic outcomes (O'Connell, Boat & Warner, 2009). As such, these factors are individual, within a family, or within a school, neighborhood and community. Importantly, parental resilience is a notable and well-established protective factor. Common protective factors are highlighted here:

Biological	<ul style="list-style-type: none"> <li>• Healthy diet and exercise</li> <li>• Healthy development</li> <li>• Secure attachment and bonding as a child</li> </ul>
Psychological	<ul style="list-style-type: none"> <li>• Reliable support and discipline from caregivers</li> <li>• Following rules at home, school and work</li> <li>• Emotional self-regulation</li> <li>• Good coping skills and problem-solving skills</li> <li>• Self-esteem</li> <li>• Optimism</li> <li>• Positive self-regard</li> </ul>
Social / School	<ul style="list-style-type: none"> <li>• Economic/financial security</li> <li>• Access to support services</li> <li>• Opportunities and recognition for prosocial involvement in school</li> <li>• Social skills</li> <li>• Emotional control and regulation</li> <li>• Interaction with prosocial peers</li> <li>• Participation in sports team, club, community or religious group</li> </ul>
Spiritual	<ul style="list-style-type: none"> <li>• Future oriented</li> <li>• Achievement motivation</li> <li>• Moral beliefs</li> </ul>

**Does depression or anxiety look the same for every NB survivor?**

The symptoms and impact of anxiety and depression can be unique for every survivor. Mental health providers (e.g., psychologists, counselors, social workers, psychiatrists) can work with individuals and families to help them understand, acknowledge, and learn to regulate their own spectrum of emotions. We all feel worried or sad sometimes — but is it getting in the way of an individual’s plans, social relationships, school, interests, or impacting personality? As a NB survivor, anxiety about health and your body may present differently than someone without experience with a serious medical condition. Acknowledging this and giving validation for your experience and noticing when you may need more support is important. Additionally, anxiety and depression are brain-based disorders, and can benefit from psychiatry interventions, including medications.

One approach to a deeper understanding of your individual emotional states is by comparing yourself to yourself. What is your level of anxiety at different times of the day, week, or year? Do you notice patterns in your own emotional states in different situations? Try monitoring this over a few days or weeks. Notice what your environment or your own types of thoughts might impact your emotions. Be curious about what you can control and what you cannot control.

***But I should be happy! I should be grateful!***

Cancer survivors often hear or say phrases like:

*“You should be \_\_\_”*

*“I should feel \_\_\_”*

*“I should be happy. I don’t have cancer anymore.”*

*“Why do I feel upset or down when people say, ‘You look good’?”*

It is important to validate your own feelings and explore where these comments of comparison, assumptions, and expectations come from. During and post-treatment you may be faced with ongoing changes in your interests, values, goals, and most importantly, what you expect of yourself. Depression and anxiety may even increase post-treatment or heighten around scans or any doctor appointments. Some experience this because they are not focused solely on medical treatment and are required to manage their pre-existing life, activities, and responsibilities outside of cancer treatment while also processing what they went through physically and emotionally during treatment.

### **What can a NB survivor do if feeling more anxious or down?**

Be honest with yourself and family members and prioritize your mental health like you do with your physical health. Make a list of what recharges your battery (e.g., friends, activities, exercise) and what drains your battery (e.g., social media, work schedules, poor boundaries). Identify the things that you can control versus things that you cannot and try focusing on the areas in your life that you can control. Many benefit from using cognitive tools learned in therapy (challenging our thinking, problem-solving), mindfulness (acceptance, living more in the moment), or behavioral tools (setting schedules or daily goals, action-oriented skills).

Acknowledge that we are not meant to do everything alone. Approach your family and social supports to ask for help, and if symptoms are persistent, seeking professional support is valid, appropriate, and recommended.

### **Where do I start? Who do I reach out to?**

There is no exact timeline for when an individual or family member may need support or interventions. It is appropriate, valid, and normal to have supports in place at any time during treatment and long into survivorship or after treatment ends.

There are many ways to connect with a mental health provider. You can reach out to your medical team or social worker for a referral to a mental health provider or program or for assistance identifying an appropriate community resource or provider to address your unique needs. There are many ways to address and improve our emotional well-being, including talk therapies, medication, and integrative medicine approaches.

A neuropsychological evaluation can be a crucial intervention during and after NB treatment to guide additional supports. A separate chapter will address signs, symptoms, and interventions around neurocognitive challenges and strengths.

Additional places to seek support and access to interventions may include:

- Hospital or cancer center psychosocial team
- Primary care teams
- School psychosocial supports: social worker, psychologist or guidance counselor
- Life clinics or long-term follow up clinics
- Community partnerships and programs (local or national groups); social media and online channels

Interventions may include:

- Talk therapies
- Psychopharmacological interventions, medication
- Integrative medicine
- Neuropsychological evaluation
- Psychoeducation
- Psychotherapy groups or support groups (online or in-person)
- Day/weekend programs, or summer camps (which often include all family members or siblings)

Please contact [info@cncfhope.org](mailto:info@cncfhope.org) with any comments.

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