

Many biopharma companies offer support to patients when initiating therapy such as verifying insurance benefits and arranging for delivery of the medication. However, substantial research indicates that people with rare or complex conditions require a broad and more intensive level of support that includes addressing the emotional needs related to their condition.

The Emotional Burden of Disease

32% of adults have reported symptoms of anxiety and/or depressive disorder related to the COVID-19 pandemic.¹

20% of patients with early-stage cancer and 80% with recurrent cancer experience symptoms of PTSD.²

40-60% excess risk of coronary heart disease is estimated to be associated with psychological stress.³

33-50% of people with diabetes experience distress.⁴

90% of people with rare diseases reported they had felt anxious, stressed, or depressed.⁵



Emotional Impact of a Serious Diagnosis

Since Dr. Elizabeth Kubler-Ross introduced her model of death and dying in 1969, subsequent and less linear paradigms of grief have been developed including this model by British psychologists Bowlby and Parkes⁶:



Shock and Disbelief
Reality becomes altered as the mind responds to a stressful situation by becoming unresponsive or numb.



Searching and Yearning
Patients may attempt to undo the new reality and question the reason for it.



Disorganization and Repair
Patients accept the new reality but may show signs of depression and apathy.



Rebuilding and Healing
Patients may experience a renewed sense of identity, overcoming the sense of loss and beginning to feel in control of their destiny.

How to Help

Patient engagement solutions are recommended that address both the clinical and non-clinical needs of patients include⁷:

Providing and explaining more information about the diagnosis helps patients better understand the disease and treatment, promotes follow-up with questions and concerns, and encourages adherence to therapy.



Engaging patients in problem-solving strategies in a supportive environment can help them work through grief, fear, and other emotions. HCPs such as Nurse Navigators provide holistic support which can address the emotional burden of disease.



Leading and/or referring patients to support groups provides patients a chance to give and receive emotional support and learn from the experiences of others.



Collaborating with the HCP care team can help patients communicate more effectively and ensure care coordination with all health care providers.



Nurse Navigators

Nurse Navigators provide digital and in-person patient support, coaching, and navigation from the time of prescription through ongoing therapy management to personalize the therapy journey based on patient needs, barriers, and learning style.



1. Kaiser Family Foundation. 2. National Cancer Institute. 3. American Journal of Medicine. 4. Mental Health America. 5. CSL. 6. NIH National Center for Biotechnology Information. 7. CDC National Behavioral Health Network.