

# Measuring Social Isolation and Loneliness: Considerations in Cancer and Chronic Disease



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# Lived Experience of Social Isolation in Cancer

Cancer is an isolating disease and beyond being consumed with treatment-related barriers to social engagement, many patients and their caregivers self-isolate.

I was out of school for 1 1/2 years, my class graduated and went on to college and work

As my husband needed more and more care, there was less support from friends and there were weeks that I didn't leave the house.

People don't know what to say, so they stop calling

I felt guilty asking for help

You get home after a day of appointments and you just don't want to do anything, especially if involves rehashing everything

They supported me in working from home, but as staff turned over, it was hard developing relations with new people

I don't want people to see me this way

Sometimes its just so awkward

I'd rather not be around casual friends who say annoying things like 'well, you don't even look like you have cancer'

# Cancer Burden| Why

**2M**

New cancers  
diagnosed  
each year

**70%**

5 year  
Survival Rate

**18.5 M**

Survivors  
in the US  
today

*More people are living with advanced and metastatic cancer than ever before*

# Cancer and Isolation| Why

There are nearly 20 million survivors in the U.S. today—more than ever before—however, many live with persistent treatment effects that limit their ability to fully participate in their life roles.

## Physical and Treatment-Related Factors

- Fatigue, pain, neuropathy, cognitive changes (“chemo brain”)
- Visible changes (hair loss, scars, ostomies, amputations)
- Immunosuppression limiting social participation

## Psychosocial Factors

- Fear of burdening others
- Changes in identity, roles, and independence
- Others’ discomfort or avoidance around cancer
- Loss of work, routine, and community engagement

## Structural Factors

- Long treatment schedules
- Extended time away from home for treatment
- Transportation challenges
- Financial toxicity limiting social activities

# Considerations in Measures and Definitions

## Measure what matters

### Subjective Considerations

Feeling disconnected or unsupported, even when others are present

Depth of meaning in social interactions

Desire for interaction and contact

Drivers of engagement/  
withdrawal

### Objective Considerations

Frequency/duration of contact or interaction

Size of networks

Level of connectedness

Self efficacy

Functional impact

Psychological impact

These likely occur simultaneously and likely interact, there may be a hierarchy, they may or may not be causative, and the relationship likely changes over time, perhaps not linearly.

# Cancer and Isolation| When

Cancer treatments last on average 3.8 years, up from 1.5 yrs just a decade ago, measurement must be done at intervals to assess meaningful changes over time.

## At Diagnosis

- Shock and uncertainty can lead to withdraw
- Care plan and treatment appointments create time burdens
- Well intentioned friends/family may come closer

## During Treatment

- Physical limitations
- Challenging schedule of treatment
- Symptom burden reduces ability to engage
- Support networks may diminish over prolonged therapy

## After Treatment

- Burden of 'new normal'
- Expectation that everything is done
- Perception that things are fine now
- Persistent and late effects

## Advanced or Metastatic

- Shrinking social circles
- Fear may drive family and friends away
- Loss of independence and function
- Existential loneliness and loss

# Considerations for Implementation

## Health Care Professionals

Professional education, including personalized training or sharing available virtual trainings

Clinical trials education and access

Normalize discussions about social connection and support engagement > check boxes

Reduce stigma, avoid assumptions, validate emotional experience

## Patient and Caregiver

Social connection is part of their story and medical experience

Education and resources

Age-specific psychosocial and mental health support and resources

Information on navigating support services

## Health Care Systems

Policies and system changes that promote screening and referrals for patients to access support.

Normalize social connection as a social determinant with a system of care for optimal management

Engage and build with community partners to fill gaps in services

Resources to address the various aspects

*Asking about loneliness can be as important as asking about pain.*

***Isolation is often an unintended consequence of treatment, not a personal failure.***

*One-size-fits-all social support does not work.*

# Priority questions to help us better understand social connection

- How do subjective feelings of isolation and loneliness relate to objective measures of loneliness? These may be related or not.
- What are the motivating factors for health systems and health care professionals to address social connection? What factors are missing?
- How do we foster linkages and natural synergies between the health care system and the communities where people live?

# Key measurement challenges

- Factors associated with the subjective feeling of loneliness and isolation and objective measures of isolation may occur simultaneously and likely interact, there may be a hierarchy, how do we assess the clustering of factors that are drivers of poor outcomes?
- Being alone may or may not be associated with a subjective feeling of loneliness. How we we assess this and identify when it changes over time, indicating greater need?
- What are the risk factors that health care professionals should assess, are they valid across different age groups, different disease types, are they different for caregivers vs patients?

Assessing and addressing  
loneliness is not an “extra” in  
cancer care, it is a core  
component of healing, dignity,  
and quality of life