The Emotional Toll of Living with Chronic Lung Disease

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The Initial Diagnosis ~ Emotional Impact

Patients can go through a wide range of emotions and mental states at the time of diagnosis of a chronic lung disease. This process is not always linear.

- Disbelief
- Confusion
- Fear
- Anger
- Sense of loss

All of this can be an exhaustive process.
The Initial Diagnosis ~ Emotional Impact

- The patient may experience confusion (e.g. “But I never smoked at all.”)

- The patient may feel a sense of responsibility and/or guilt if they did or are using tobacco.

- The patient may experience existential questions, such as ‘Why me?’ or ‘Have I lived a good life?’

- The patient may feel at a loss about how to implement life changes that are now required due to the diagnosis.
The Initial Diagnosis ~ Emotional Impact

The mental and emotional impact to the patient can also depend on the type of diagnosis and the functional status of the patient at the time of diagnosis.

- If the patient is otherwise feeling well, yet is diagnosed with a lung cancer, it may be harder for them to believe and accept their medical situation.

- If the patient is not well and is diagnosed with COPD, they may initially feel relief at knowing what is wrong, yet frustrated and disappointed when they learn there is no cure.
The Initial Diagnosis ~ Emotional Impact

- Because lung disease affects such vital organs, these diagnoses can be quite devastating to patients (and caregivers) as they imply that the patient will have a shortened life span.

- Patients also have to contend with the stigma associated with lung disease, even though lung cancer can occur in non-smokers and COPD and asthma can be caused by genetic or environmental factors.
The Initial Diagnosis ~ Emotional Impact

And then there is breathlessness…

Patients can experience the following due to chronic breathlessness:

- Anxiety, fear and/or panic
- Exhaustion
- The loss of progressive functional decline
- More exhaustion due to sleeplessness
The Pursuit of Treatment ~
the Journey of Decision-Making

- Deciding on a treatment path often involves testing for appropriate treatment options.

- Patients may have understandable fears about a major surgery, chemotherapy and/or radiation treatment.

- Testing and treatment can be hard on the patient if there is a lack of explanation of what to expect or lack of information on how to minimize side effects.

- Lack of information leads to extra worry for the patient.
The Pursuit of Treatment ~
the Journey of Decision-Making

- Decision-making around treatment for lung disease has to be fairly rapid and is informed and affected by the patient’s exhausted state.

- Decisions about treatment can be influenced by a strong desire to regain normal breathing.

- Physical and/or mental exhaustion can also influence a patient’s decision regarding whether to treat or to engage in palliative care and/or enroll in hospice.
The Pursuit of Treatment ~
the Journey of Decision-Making

- Recommendations for treatment may conflict with the patient’s life goals.

- Patients may experience confusion if it hasn’t been explained to them why certain treatment options are not appropriate for their situation.

- Some patients may not be integrating that the diagnosis of lung disease is happening to them.
The Emotional Toll on the Patient

The chronic lung disease patient can experience a range of emotions related to their diagnosis.

- Anger at their situation
- Frustration at being or feeling dependent on others
- Resentment that others can keep living normally or at caregivers who might tend to hover
- Guilt about being a burden to others
- Sense of being alone
The Emotional Toll on the Patient

The chronic lung disease patient often experiences progressive losses.

- Loss of stamina
- Loss of activity level and enjoyable activities
- Loss of social interaction
- Loss of intimacy or connection with a partner/spouse
- Loss of ability to work (professional identity)
- Loss of income
The impact of all of these losses and emotions can make everyday life extremely difficult to navigate.
The Emotional Toll on the Patient

It is important to be gentle with yourself and take things one day, one moment at a time.
The Emotional Toll on the Family

The family of the chronic lung disease patient also experiences many emotions.

- Caregiver/family may experience extreme worry about the patient

- Feelings of overwhelm at adjusting to caregiving role

- Helplessness at watching their loved one gasp for air

- Children and grandchildren may not understand the changed functional status of the patient

- Disappointment at not being able to fully enjoy family fun and relaxation

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Caregiver Losses

The caregiver of the chronic lung disease patient may also experience a number of losses.

- Companionship
- Connection/Intimacy
- Freedom to come and go as desired
- Isolation
- Lost time at work
- Lost income and financial stability
The Emotional Toll on the Family

The impact of all of these losses and emotions can make everyday life extremely difficult to navigate.
It is important to be gentle with yourself and take things one day, one moment at a time.
How the Patient Copes

Physicians and clinicians can assist patients in coping:

- Education from physicians
  - Diagrams for patients are helpful
  - Correlate bodily processes to everyday life

- Pulmonary rehabilitation

- Hospital social work services can connect patients to community and financial resources

- Encourage patients to stay engaged in life as much as possible

- Tell patients: “Don’t be afraid to ask questions or ask for help.”
How the Patient Copes

Resources that clinicians can provide and patients can seek out:

- Acupuncture
  - Helpful for smoking cessation
  - Can assist in helping anxious patients relax

- Guided imagery, mindfulness and other mind-body integrative or energy based modalities

- Counseling support

- Connection with lung disease organizations such as Lung Force, CancerCare and Lungevity.
Ten Tips for Coping as a Patient

- Designate a healthcare proxy
- Gather information from, and ask questions of, reliable sources of medical information
- Avoid information overload
- Understand and work toward accepting physical limitations, hope for improvement in future
- Pace yourself
- Investigate palliative care and hospice care
- Develop adaptive coping mechanisms
- Adapt hobbies to meet your current abilities
- Seek support from family, friends and/or professionals
- Find your “motivator”
How the Caregiver/Family Copes

Physicians and clinicians can assist caregivers in coping:

- Refer family members to hospital caregiver support groups
- Refer family members to support organizations
- Encourage the caregivers to do their self-care, avoid isolation and ask family and friends for help
- Tell caregivers: “Encouragement of patients works better than negative reinforcement.”
  “If the patient is irritable, it is not about you, it’s about their situation.”
  “You are not alone.”
How the Caregiver/Family Copes

Resources that clinicians can provide and caregivers can seek out:

- Professional counseling support
- Assistance from your social network, if it is truly helpful to you
- Guided imagery, mindfulness and other mind-body integrative or energy based modalities for self-care
- Peer support
- Connection with lung disease organizations such as Lung Force, CancerCare and Lungevity.
Ten Tips for Coping as a Caregiver

- Engage in self-care (breathe)
- Pace yourself as a caregiver
- Become informed while avoiding information overload
- Take advantage of a support group, in person or on-line
- Avoid isolation by tapping into your circle of family and friends
- Learn to delegate
- Talk with your loved one about your concerns
- Develop adaptive coping skills
- Seek support from family, friends and/or professionals
- Remember your self-care (self-care is not selfish)
Supporting Each Other

- Listen and hear the other person when talking
- Share resources and tips
- Remember to do your self-care before helping others
Supporting Each Other

- Take a lung disease holiday for the afternoon
Supporting Each Other

- Help each other remember to do self-care
Supporting Each Other

- Spend quality time with loved ones
Supporting Each Other

❖ Review positive memories and make new ones
Thank You

This presentation was created with gracious input from the following people:

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- Jordan Gromek, LSW
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Resources

- Lung Force (American Lung Association)  
  www.lungforce.org
- CancerCare – www.cancercare.org  1.800.813.4673 (HOPE)
- LUNGevity - www.lungevity.org
- Center to Advance Palliative Care (CAPC)  
  www.getpalliativecare.org
- Patient Advocate Foundation (PAF)  
  www.PatientAdvocate.org