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Coping with a Chronic Disease

Scleroderma presents quite a challenge for people who have it. It's difficult for family members and friends, too. When you try to cope with any illness, attitude counts almost as much as medication and treatments. This lecture explains how the following principles can make a big difference in how people with scleroderma can live better with it.

First: the Principle of Human Behavior

- All behavior has a reason. Generally people act the way they do to:
- Avoid psychological discomfort, retain their self-confidence and stay comfortable physically and emotionally

Second: The Light Bulb Principle

- How many psychiatrists does it take to change a lightbulb?
- Only one, but the lightbulb has to want to change! So if you want to change your behavior or anyone else's, you and they have to want that change to happen.

Third: The Chronic Disease Principle

- Chronic disease gets worse and then gets better and then might get worse again. It never goes away. Sometimes you can prevent a worsening of the disease and sometimes you can't. You shouldn't blame yourself or anyone else if your disease gets worse. There is always something you can do to feel better, even if it doesn't feel that way at the time.

Fourth: Who's in Charge Here?

- Are you in charge of your disease and your life? If not, why not? How can you take control of your life again?

Coping definitions:

- ...to successfully manage distress and the problem underlying the distress
- ...a process as well as an outcome
- ...coping successfully with a stressor may increase the body's ability to fight infection, decrease depression and increase a feeling of well-being, even though the disease continues

What is successful coping?

- Continuing to function in daily life while taking care of yourself and the disease
- Recognizing abilities and disabilities

- Integrating needs of the disease with needs to maintain real life

There is a long list of challenges that scleroderma patients have to cope with, including disability, changes in body, especially hands and face, loss of work, loss of ability to do work at home, and pain.

How do people cope badly?

- Hide from/deny
- Stay depressed
- Use drugs/ETOH
- Push people away
- Focus only on what you have lost
- Become a victim
- Blame
- Stay angry
- Ignore your symptoms

How can people cope well?

- Recognize & accept emotions
- Educate yourself
- Hunt for the right doctor
- Find support/have fun
- Ask for/Accept help
- Treat yourself to_____
- “Defy the verdict”
- Other?

Resources

- Susan Folkman <http://teachpsych.lemoyne.edu/teachpsych/faces/text/Ch01.htm>
- Fumi O. Naughton
- Margaret Kemeny

- http://cancerresources.mednet.ucla.edu/5_info/5c_archive_lec/5c00_archive_lecture.htm
- Vanessa Malcarne: Chapter 23 in Systemic Sclerosis, 2nd edition, by Clements & Furst, editors.
- The First Year: Scleroderma from a patient's perspective by Karen Gottesman
- Check the books listed on www.scleroderma.org

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At håndtere en kronisk sygdom

Sklerodermi er en stor udfordring for dem der har det. Det er også svært for familie og venner. For at håndtere en hvilken som helst sygdom tæller holdning næsten ligeså meget som medicin og behandling. Denne lektion forklarer hvordan følgende principper kan gøre en stor forskel i hvordan mennesker med sklerodermi bedre kan leve med den.

For det første: Det menneskelige adfærd

Al adfærd sker af en årsag - generelt opfører mennesker som de gør for:
at undgå fysisk ubehag, for at bibeholde deres selvtilid og for at forblive fysisk og psykisk /comfortable/

For det andet: Lysepære princippet

Hvor mange psykiatere skal der til for at skifte en pære?

Kun en, men pæren skal ønske at blive skiftet! Så hvis du vil ændre din egen eller en andens opførsel, så skal du eller han/hun ønske den ændring

For det tredje: Princippet bag den kroniske sygdom

Kronisk sygdom bliver værre og bliver så bedre, og så kan det være at det bliver værre igen. Den forsvinder aldrig. Sommetider kan du forhindre en forringelse af sygdommen og sommetider kan du ikke. Du skal ikke bebrejde dig selv eller andre hvis din sygdom bliver værre. Der er altid noget, du kan gøre bedre, også selvom det ikke føles sådan mens det står på.

For det fjerde: Hvem bestemmer her?

Bestemmer du over din sygdom og dit liv? Hvis ikke, hvorfor ikke? Hvordan kan du tage kontrollen over dit liv igen?

Håndteringsdefinitioner:

- .. for med succes at håndtere sin nød og det underliggende problem for nødden
- .. det er en process ligesåvel det har et resultat
- .. at håndtere et stressmoment med succes kan øge kroppens evne til at bekæmpe infektion, håndtere depression og øge følelsen af velvære, selvom sygdommen stadig er der

Hvad er succesfuld håndtering:

- .. at fortsætte med at fungere i det daglige liv mens du passer på dig selv og sygdommen
- .. at acceptere hvad du kan og ikke kan
- .. at integrere dine behov fra sygdommen til behov for at opretholde liv

Der er en lang liste af udfordringer som sklerodermi patienter må håndtere/leve med, handicaps, kroppens ændringer især hænder og ansigt, tab af arbejde, tabet af muligheden for rengøring, og smerter.

Hvordan håndterer patienter det DÅRLIGT:

- ... skjuler sig/benægter
- ... forbliver i depressivt humør
- ... bruger stoffer
- ... skubber folk væk
- ... fokuserer kun på hvad de har mistet
- ... bliver et offer
- ... giver skylden til...
- ... forbliver vred
- ... ignorerer symptomerne

Hvordan kan man håndtere det GODT:

- ... genkender og accepterer følelserne
- ... uddanner sig selv
- ... jager den rette læge
- ... finder support/og morskab
- ... beder om/accepterer hjælp
- ... forkæler dig selv med....
- ... "Trods dommen"
- ... andet??

Kilder:

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