



Affairs of the Heart

LUPUS & RELATIONSHIPS

Lupus & Relationships

- ▶ Maintaining healthy friendships
- ▶ The fear of dating
- ▶ Successful communication
- ▶ Intimacy
- ▶ Staying connected

Friendships

- ▶ Vital to your support system
- ▶ Discover who your true friends are
- ▶ Dealing with a loss of friendship
- ▶ Different types of friends

Family

- ▶ Common for family members to be unrealistically positive
- ▶ Know what your family can handle
- ▶ Communicate what your needs are & how your family can help
- ▶ Acknowledge unique family dynamics

Dating & Relationships

In sickness and in health...

Lupus & Dating

- ▶ Fear of dating
 - ▶ Dating in general
 - ▶ Don't want to subject someone else to your illness
 - ▶ Fear of rejection because of your illness
 - ▶ How do you plan for a date when you might have a flare?
- ▶ Make sure that you're ready & emotionally available
- ▶ Finding the right person and a forever partner makes it all worth it

- ▶ <http://www.butyoudontlooksick.com/articles/written-by-christine/the-lupus-dating-game/>

Lupus & Dating

- ▶ Disclosure
 - ▶ Too soon = scare away
 - ▶ Too late = lack of trust
 - ▶ What's right for you?
 - ▶ What is Lupus?
 - ▶ How does Lupus impact your life?

Recent Diagnosis

- ▶ Recent diagnosis
 - ▶ Go through the grieving process together but at your own pace
 - ▶ How will Lupus change your relationship?
- ▶ Five Stages of Grief - Elizabeth Kubler- Ross
 - ▶ Denial
 - ▶ Anger
 - ▶ Bargaining
 - ▶ Depression
 - ▶ Acceptance

Communication

- ▶ Basic key to any strong and successful relationship
- ▶ Lack of communication can lead to feelings of distance and lack of intimacy
- ▶ Listen
- ▶ "I" Messages versus "You" Messages
- ▶ Verbalize your needs
 - ▶ Be direct – your partners is not a mind reader
 - ▶ Know when to ask for help
- ▶ Nonverbal signals
 - ▶ Body language
 - ▶ Facing away
 - ▶ Folding arms
 - ▶ Lack of eye contact
 - ▶ Louder tone
- ▶ Focus on here and now
- ▶ Other ways of communicating
 - ▶ Actions

Communication Continued

- ▶ Be conscious of your loved one and how they're feeling
 - ▶ Take time to acknowledge your partners needs as well
 - ▶ Don't be consumed by your illness
 - ▶ Find a middle ground
 - ▶ Put yourself in their shoes
- ▶ Shift in balance within a relationship
 - ▶ Role changes
 - ▶ Feeling like a patient and not a partner
- ▶ It takes two – Know when it's time to compromise

Communication Continued

- ▶ Create a safe space or designated time
 - ▶ Area in your home or a place you go to together
 - ▶ Time dedicated to communicating openly and honestly
 - ▶ Write down your feelings or write a letter to your loved one
- ▶ Make a conscious effort to find ways to show each other that you love and care for each other
 - ▶ Plan something special monthly, tell your partner how much they mean to you

Lupus & Relationships

- ▶ Positive spin to loving with Lupus
 - ▶ Team
 - ▶ Support
 - ▶ Love unconditionally

Lupus & Intimacy

LFA Study

- ▶ 1/3 of people with lupus reported decrease in desire for sexual intimacy
- ▶ Almost 1/2 avoided sex due to lupus flares
- ▶ 40% felt that their relationships were negatively affected due to lupus

- ▶ Social, emotional, mental & spiritual aspects

Lupus & Intimacy

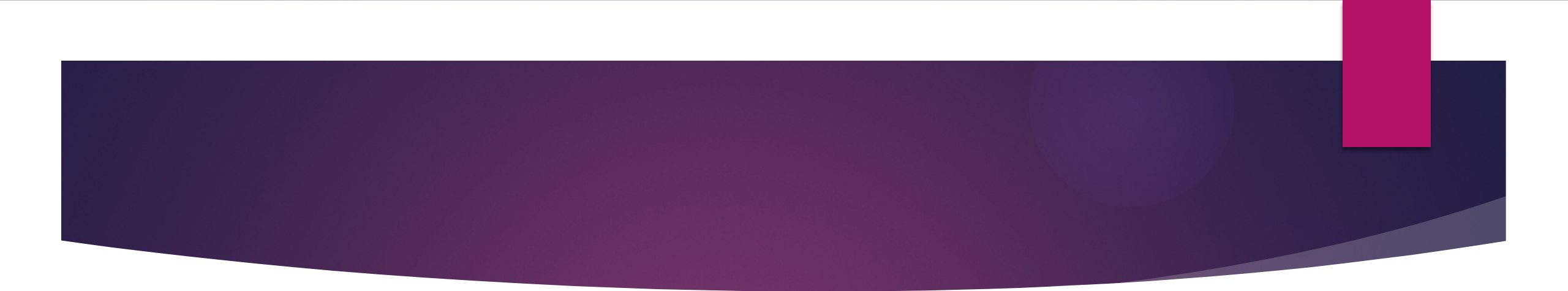
- ▶ Desire but no energy
- ▶ Spoon Theory
 - ▶ Where does intimacy fall on your list
- ▶ Depression or low self-esteem
 - ▶ Effect our ability to be intimate with our partners
- ▶ How you perceive yourself & how you share yourself with others
- ▶ Medications
 - ▶ Body image/physical perception of self
 - ▶ Weight gain/rashes
 - ▶ Antidepressants and other side effects

Lupus & Intimacy

- ▶ Pain/discomfort
 - ▶ Positioning and joint pain
 - ▶ Be creative - figure out what works for you
 - ▶ Vaginal dryness
 - ▶ Sensitive skin
 - ▶ Birth control
- ▶ Intimacy without intercourse

Self Care

- ▶ Self care
 - ▶ Pamper yourself
 - ▶ Take some time for you
- ▶ Make a list of positive qualities
- ▶ Practice positive affirmations
- ▶ Journal

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- ▶ Be grateful for what you have
 - ▶ Stay positive
 - ▶ Passion
 - ▶ Self-reflect

Stay Connected

- ▶ Stay connected and socially engaged
- ▶ Be proactive

- ▶ Support groups
- ▶ Internet forums
- ▶ Therapy

"I know that in life there will be sickness, devastation, disappointments, heartache – it's a given. What's not a given is the way you choose to get through it all. If you look hard enough, you can always find the bright side." –
-Rashida Jones



"The secret of health for both mind and body is not to mourn for the past, not to worry about the future, or not to anticipate troubles, but to live in the present moment wisely and earnestly."
- Buddha



"We've got this gift of love, but love is like a precious plant. You can't just accept it and leave it in the cupboard or just think it's going to get on by itself. You've got to keep watering it. You've got to really look after it and nurture it." – John Lennon