

# FASD: Supporting Caregivers- Success for All

FASD Waterloo Region  
Kitchener, Ontario  
February 21, 2019



1

---

---

---

---

---

---

---

---

**Dan Dubovsky, MSW**  
**FASD Specialist**

[ddubovksy@verizon.net](mailto:ddubovksy@verizon.net)  
215-694-8450



2

---

---

---

---

---

---

---

---

## Objectives

- ▶ By the end of this session, participants will be able to:
  - Identify loss issues that those with FASD, caregivers, and providers may experience
  - Describe ways to validate the perspective of caregivers
  - Examine the importance of building social supports for caregivers
  - Discuss the notion of introducing the concept of self-care



3

---

---

---

---

---

---

---

---

## Facilitating Groups

- ▶ How groups are facilitated is key to their success
- ▶ Facilitation is often not as simple as we think
- ▶ It takes enthusiasm, caring, confidence, planning, education, consistency
- ▶ ...and food ☺
- ▶ Having co-facilitators is important



4

---

---

---

---

---

---

---

---

## Co-facilitation of Groups

- ▶ Co-facilitators support each other
- ▶ Meet physically or virtually to process what occurred in the group, what could be better, and plan for the next group
- ▶ Decide who will take the lead on what part of the group session



5

---

---

---

---

---

---

---

---

## Co-facilitation of Groups

- ▶ If one group member is having difficulty, it allows one facilitator to speak with that person and not disrupt the whole group
- ▶ If one facilitator is ill or cannot attend, the group does not need to be cancelled



6

---

---

---

---

---

---

---

---

### First Group

- ▶ Plan ahead
- ▶ Introductions
  - What do you want people to know about you?
  - What do you like to do?
- ▶ Ask each person what he or she hopes to get out of the group

---

---

---

---

---

---

---

---



7

### First Group

- ▶ Assess language and cultural issues from group members
  - Ensure you take these into account
  - Regularly check in regarding true understanding
- ▶ Have the group determine the rules
  - Write them down and give them to members at the next meeting

---

---

---

---

---

---

---

---



8

### Possible Group Structure

- ▶ Introductions
- ▶ Check in on "homework" from the week before
- ▶ Provide an educational component
- ▶ Allow time for questions
- ▶ Check in on how people are doing
  - This can be done before the educational component or after depending on the group
- ▶ Provide a self-care exercise
  - Encourage people to try it before the next meeting

---

---

---

---

---

---

---

---



9

### Importance of Group Topics

- ▶ Introductions help people feel connected
- ▶ Check in on “homework” supports the importance of self-care
- ▶ Educational component helps people feel that they are learning something new or reinforcing something that they know
- ▶ Time for questions encourages each person to be heard



10

---

---

---

---

---

---

---

---

### Importance of Group Topics

- ▶ Check in on how people are doing/what has been happening since the last meeting conveys that you are interested in what everyone has to say
  - Encourage people to share but do not require it
  - Validate what people share (you don't have to agree)
  - Thank people for sharing
  - Be delicate in ensuring that everyone has time to share and one or two people don't dominate



11

---

---

---

---

---

---

---

---

### Importance of Group Topics

- ▶ Self-care stresses the importance of caregivers taking care of themselves
  - People cannot optimally care for others if they do not care for themselves
  - Practice if appropriate
- ▶ Suggest they try at least once between meetings
- ▶ Discuss how to implement the self care
  - Identify possible barriers
  - Identify ways to overcome them



12

---

---

---

---

---

---

---

---

### Possible Self-Care

- ▶ Guided imagery
- ▶ Deep breathing
- ▶ Meditation
- ▶ Yoga/Tai Chi
- ▶ Healthy diet
  - A treat from time to time is important
  - Eat regular meals
- ▶ Regular sleep routine
- ▶ Participate in a spiritual/cultural activity



13

---

---

---

---

---

---

---

---

### Possible Self-Care

- ▶ Reading a “fun” book
- ▶ A hobby
  - Preferably one that results in a finished project
- ▶ Exercise and/or play a sport
- ▶ Going for a walk regularly
- ▶ Taking a relaxing bath
- ▶ Listening to music you love
- ▶ Keep a journal



14

---

---

---

---

---

---

---

---

### Possible Self-Care

- ▶ Go to the movies
- ▶ Go out with friends
- ▶ Set aside time for close relationships
  - Partners, children, other family
  - Do a fun activity regularly
- ▶ leave work at work to have time for home at home
- ▶ Laugh every day



15

---

---

---

---

---

---

---

---

## Why Self-Care is Important

Noma Nazish for Forbes

- ▶ Know your worth
- ▶ A healthy work-life balance
- ▶ Stress management
- ▶ Start living, stop existing
- ▶ Better physical health

<https://www.forbes.com/sites/payout/2017/09/19/practicing-self-care-is-important-10-easy-habits-to-get-you-started/#46584de4283a>



16

---

---

---

---

---

---

---

---

## Resources for Self-Care

- ▶ There are many resources for self-care that can be found
- ▶ A few books are:
  - ▶ Self-Care for the Real World: Practical Self-care Advice for Everyday Life by Katia Narain Phillips and Nadia Narain
  - ▶ The Little Book of Self-Care by Mel Noakes
  - ▶ The Self-Care Project: How to Let Go of Frazzle and Make Time for You by Jayne Hardy



17

---

---

---

---

---

---

---

---

## Possible Educational Topics

- ▶ Brain issues in FASD and how they affect behavior
- ▶ Affect regulation
- ▶ The importance of social supports for caregivers
- ▶ Stress and the prevention of burnout
- ▶ Loss and grieving
  - The importance of acknowledging and addressing it



18

---

---

---

---

---

---

---

---

### Possible Educational Topics

- ▶ Mental health issues in FASD
- ▶ Assertiveness vs aggressiveness
- ▶ The importance of social supports for families
  - Without these, families tend to get insulated and focus on the negative behaviors of their loved one
- ▶ Person first language
- ▶ Using a positive focused system
- ▶ Ways to think about behaviors



19

---

---

---

---

---

---

---

### Keys to Remember When Raising Youth with an FASD

- ▶ Always ask what is causing a behavior before responding to it
  - The cause tells us how we need to respond
- ▶ Think about what age the behavior that you are seeing feels like
  - Instead of getting angry at the behavior, we can then understand it and respond differently
- ▶ Consider loss issues



20

---

---

---

---

---

---

---

### Why Think About Loss and Grieving

- ▶ We often only think about loss and grief in terms of death
- ▶ All individuals with an FASD have experienced multiple losses
  - They are not like their peers as they get older
- ▶ All families experience multiple losses
- ▶ Sometimes, behaviors that we see are reflections of issues around loss
  - If we don't recognize that, we may not respond in a helpful way



21

---

---

---

---

---

---

---

*If we do not in some way mourn our losses, we end up living in the past, regretting the present, and fearing the future.*

• Elizabeth Kübler-Ross



22

---

---

---

---

---

---

---

---

### Physical Manifestations of Grief

Adapted From Pickett (1993)

- ▶ Hollowness in the stomach
- ▶ Tightness in the chest and throat
- ▶ Shortness of breath
- ▶ Oversensitivity to noise
- ▶ Muscle weakness
- ▶ Lack of energy
- ▶ Dry mouth
- ▶ Hallucinations
- ▶ Mask-like face



23

---

---

---

---

---

---

---

---

### Behaviors Associated With Grief

Adapted From Pickett (1993)

- ▶ Sleep disturbances
- ▶ Appetite disturbances
- ▶ Absent-minded behavior
- ▶ Social withdrawal
- ▶ Distressing dreams
- ▶ Sighing
- ▶ Restlessness
- ▶ Crying
- ▶ Anger outbursts
- ▶ Mood swings



24

---

---

---

---

---

---

---

---

### Losses Experienced by Persons With FASD or Other Disabilities

Dubovsky (1996)

- ▶ Hopes and dreams
- ▶ Self-esteem and competence
- ▶ Balanced family system
- ▶ Peer relationships
- ▶ Intimate relationships
- ▶ Support from others



25

---

---

---

---

---

---

---

---

### Losses Experienced by Persons With FASD or Other Disabilities

Dubovsky (1996)

- ▶ Their family (through separations)
- ▶ Consistent caregivers
- ▶ Vocational/educational opportunities
- ▶ A role in the family and in society
- ▶ Joy and pleasure



26

---

---

---

---

---

---

---

---

### Losses Experienced by Persons With FASD or Other Disabilities

Dubovsky (1996)

- ▶ Potential/talents
- ▶ Companionship
- ▶ The ability to be like everyone else
- ▶ Freedom
- ▶ Security about the future
- ▶ Control



27

---

---

---

---

---

---

---

---

### Losses Experienced by Families

Dubovsky (1996)

- ▶ Hopes and dreams
- ▶ Self-esteem and competence
- ▶ Balanced family system
- ▶ Support from family, friends, community



28

---

---

---

---

---

---

---

---

### Losses Experienced by Families

Dubovsky (1996)

- ▶ Companionship
- ▶ Their loved one (placement, suicide, leaving the family)
- ▶ Faith
- ▶ Financial security
- ▶ Privacy



29

---

---

---

---

---

---

---

---

### Losses Experienced by Families

Dubovsky (1996)

- ▶ Freedom
- ▶ Social network
- ▶ The ability to "kvell"
- ▶ Security about the future
- ▶ Control



30

---

---

---

---

---

---

---

---

### Blame Checklist

Dubovsky (1998)

▶ Check off all those whom you can blame for the problems you encounter:

- Yourself -----
- Your significant other -----
- Genetics -----
- "The system" -----
- Infomercials -----
- Aliens -----
- The line-up of the planets -----
- A superior being -----



31

---

---

---

---

---

---

---

---

### Losses Experienced by Providers

Dubovsky (1998)

- ▶ Hopes and dreams
- ▶ Self-esteem and competence
- ▶ Relationships
- ▶ The ability to "kvell"
- ▶ Faith
- ▶ Security about the future
- ▶ Control



32

---

---

---

---

---

---

---

---

### Risk Factors for Prolonged Grief

Dubovsky (1998)

- ▶ History of multiple losses
- ▶ History of incomplete management of grief
- ▶ Inadequate social supports
- ▶ Unrecognized or stigmatized loss
- ▶ Social isolation



33

---

---

---

---

---

---

---

---

## Tasks That Grieving Persons Need to Perform

Adapted from Rosen (1990)

- ▶ The family's shared knowledge and acceptance of the reality of the loss
- ▶ The family's shared experience of the pain of grief
- ▶ Reorganization of the family system
- ▶ Redirection of relationships and goals



34

---

---

---

---

---

---

---

---

## Providing Help to Individuals and Their Families

Dubovsky (1996)

- ▶ Really listen
- ▶ Be honest
- ▶ Raise awareness of experiences of separation and loss
- ▶ Acknowledge losses experienced



35

---

---

---

---

---

---

---

---

## Providing Help to Individuals and Their Families

Dubovsky (1996)

- ▶ Validate losses experienced
- ▶ Avoid "good parent/bad parent" issues
- ▶ Support confronting losses in a positive manner
- ▶ Encourage communication



36

---

---

---

---

---

---

---

---

## Providing Help to Individuals and Their Families

Dubovsky (1996)

- ▶ Genuinely care
- ▶ Be there for support
- ▶ Acknowledge your own feelings about loss
- ▶ Refer for treatment when necessary

---

---

---

---

---

---

---

---



37

## A Strengths Based Approach to Improving Outcomes

- ▶ Identify strengths and desires in the individual
  - What do they do well?
  - What do they like to do?
  - What are their best qualities?
  - What are your funniest experiences with them?
- ▶ Identify strengths in the family
- ▶ Identify strengths in the providers
- ▶ Identify strengths in the community
  - Include cultural strengths in the community

---

---

---

---

---

---

---

---



38

### Bill's Strengths

- ▶ Friendly
- ▶ Likeable
- ▶ Verbal
- ▶ Helpful
- ▶ Endearing
- ▶ Caring
- ▶ Animal lover
- ▶ Funny
- ▶ A good heart
- ▶ Determined
- ▶ Points of insight
- ▶ Good with younger children
- ▶ Willing to try new things
- ▶ Not malicious
- ▶ Public Speaking
- ▶ Every day is a new day



---

---

---

---

---

---

---

---



39

## Stress Management



40

---

---

---

---

---

---

---

---

### The Importance of Acknowledging and Dealing with Stress

- ▶ We all experience stress in our lives
  - We may experience stress in our work life, our home life, our personal life
- ▶ We all handle stress differently
- ▶ Stress affects our physical and emotional health
- ▶ We often dismiss the stress we experience
- ▶ If we don't find a way to manage stress, it continues to build and leads to burnout
  - If we ignore it, it does not go away
- ▶ Stress causes the release of cortisol
  - A little is good; a lot is not



41

---

---

---

---

---

---

---

---

### Compassion Fatigue

- ▶ The cost of caring
- ▶ Physical, emotional, and/or spiritual fatigue that takes over a person
- ▶ Causes a decline in the ability to experience joy and care for oneself or others
- ▶ If stress is not addressed, it builds and interferes with day to day functioning
- ▶ Experienced by human service personnel as well as families



42

---

---

---

---

---

---

---

---

## The Worry Grid

- ▶ The purpose of the worry grid is to get a handle on addressing stress in your life
- ▶ There are several steps in the process
  - Identify your worries
  - Construct a grid
  - Identify what you can and cannot address
  - Develop steps to address that which you can control



43

---

---

---

---

---

---

---

---

## Ten Steps Towards Managing Stress

(Eshelman et al 1988)

- ▶ Identify symptoms of stress
- ▶ Identify sources of stress
- ▶ Identify how you respond to your particular stressors
- ▶ Set goals to respond more effectively
- ▶ Motivate yourself



44

---

---

---

---

---

---

---

---

## Ten Steps Towards Managing Stress

(Eshelman et al 1988)

- ▶ Change your thinking
- ▶ Deal with others
- ▶ When in conflict, negotiate
- ▶ Pace and balance yourself
- ▶ Know when to quit



45

---

---

---

---

---

---

---

---

### Tips for Managing Stress

- ▶ Clearly describe the situation that is causing stress
- ▶ Be aware of how you currently handle stress
  - Set a task to “observe yourself” and how you react
- ▶ Brainstorm alternative responses at times that are not stressful
  - Write down the alternatives
- ▶ Set realistic goals for yourself
  - Not “change all my reactions in every situation now”



46

---

---

---

---

---

---

---

---

### Tips for Managing Stress

- ▶ Make effective use of your time
  - Write a **realistic** “to do” list
  - Set priorities
  - Check off items accomplished
- ▶ Find something to “finish”
- ▶ Eat correctly
- ▶ Get enough sleep



47

---

---

---

---

---

---

---

---

### Tips for Managing Stress

- ▶ Exercise regularly
- ▶ Practice deep breathing
- ▶ Do what relaxes you
  - Listen to music
  - Take a hot bath
  - Get a massage
  - Read
- ▶ Learn progressive relaxation techniques
- ▶ Leave work at work



48

---

---

---

---

---

---

---

---

### Tips for Managing Stress

- ▶ Take time for yourself
  - Take an hour or a day for yourself
  - Take regular vacations
  - Use sick time when sick
- ▶ Find a way to have fun
  - At home
  - At work
- ▶ Do something that results in a concrete product
  - Art; craft; writing
  - You may have to find something that can be completed in a short period of time



49

---

---

---

---

---

---

---

---

### Tips for Managing Stress

- ▶ Identify strengths in yourself and those around you
  - Write down each person's strengths
  - Review them regularly
  - Add to the lists
- ▶ Give yourself credit for what you do accomplish and have accomplished in the past
- ▶ Don't take on inappropriate guilt
  - Try not to take on the "superperson" or "rescue" syndrome
- ▶ Recognize there is a balance of "success" and "failure"
- ▶ Forgive others and yourself



50

---

---

---

---

---

---

---

---

### Tips for Managing Stress

- ▶ Have faith in yourself and others
- ▶ Keep in touch with your spirit
- ▶ Love and appreciate yourself
- ▶ Take care of yourself
- ▶ Keep a sense of humor
- ▶ RELAX!!



51

---

---

---

---

---

---

---

---

### Keys to Remember When Raising Youth with an FASD

- ▶ We can't be fair if we treat everyone the same
- ▶ Identify positives in those for whom you are caring
- ▶ Think about their strengths and abilities
  - It helps to write them down
- ▶ When things go poorly, remember what has gone right
- ▶ Find something to smile about every day



---

---

---

---

---

---

---

---

### Keys That Caregivers Need to Hear

- ▶ How those they care for behave is not their fault
- ▶ What they are doing to support the person is very valuable
- ▶ They may not see the results of what they do right away but what they do matters
- ▶ It's OK to say "I don't know"
- ▶ It's OK to say "I need a break"
- ▶ It's important to have a safe place to vent



---

---

---

---

---

---

---

---