

Building Compassion-Based Relationships with Families & Other Caregivers

Section 12



INTRODUCTION

“Engagement is often viewed as synonymous with involvement. Involvement in services is important, but real engagement goes beyond that. Families can be involved and compliant without being engaged. Engagement is motivating and empowering families to recognize their own needs, strengths and resources and to take an active role in changing things for the better. Engagement is what keeps families working in the sometimes slow process of positive change” –Sue Steib (2004).



INFORMATION

[Distribute this document to all participants to explore prior to the following application activities.](#)



APPLICATIONS

Key Activity

Compassionate Connections with Families or Caregivers

Wellness Practice

Bringing It All Together Through My Hands — An activity to summarize compassion and self-compassion found in the document to distribute in the information section of the toolkit

Circle Agenda

[Responding to Challenging Interactions with Families – handout and possible role-play activity](#)

Supplementary Activities/Handouts

[Responding to Challenging Interactions with Families – handout and possible role-play activity](#)

[Communicating Difficult News to Clients and Their Families](#)

[Stages of Change Applied to Family Conversations Adopting a Strengths-Based Approach](#)



LINKS

For links to additional resources, please visit the [Toolkit online](#).

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“Engagement is often viewed as synonymous with involvement. Involvement in services is important, but real engagement goes beyond that. Families can be involved and compliant without being engaged. Engagement is motivating and empowering families to recognize their own needs, strengths and resources and to take an active role in changing things for the better. Engagement is what keeps families working in the sometimes slow process of positive change.” – Sue Steib (2004).

Families, however they are defined, are often essential to the health and well-being of clients and can be crucial allies for providers in the delivery of care. Engaging families as active participants in a client- and family-centered approach can have positive effects on health outcomes and experiences of care as well as provider satisfaction.

The opportunities providers have for engaging and building relationships with families and other caregivers, however, can leave them vulnerable to compassion fatigue too. The drivers of compassion fatigue can be very similar to those that drive compassion fatigue around clients. When we come to understand the trauma families are facing or have faced, try to meet sometimes unrealistic expectations, and/or feel ineffective in building positive relationships with families, it can lead to behaviors that are signs of compassion fatigue. We do not have to look far to hear providers identifying families and other caregivers as “difficult,” entering family engagement with vigilance, using a client’s home life as an explanation for a lack of improvement, and not wanting to get to know the family context of their clients. Of course, a similar story is true in reverse: It can be challenging, and not uncommon, to hear families blaming providers for the challenges their family members face and spending time building fences rather than bridges.

So, how do we recognize that we are on the same team and learn to “tag-team” our support for the people we serve? Clearly, there are benefits when the game plan is designed together and goals are understood and communicated. The biggest benefit of a successful provider-family collaborative team, other than the health and well-being of the client, may be the decrease of compassion fatigue for both the provider and the family.

Rather than labeling a family or other caregiver as “difficult” or entering an encounter with vigilance, consider the following beliefs for family engagement:¹

- 1. All families want the best for their family members.**
- 2. All families have the capacity to support their family member’s health and well-being.**
- 3. Families and providers are equal partners.**
- 4. The responsibility for cultivating and sustaining partnerships among health care organizations, providers, families and community rests primarily with health care providers and leaders.**

¹ Institute for Patient- and Family Centered Care. (n.d.). Patient- and family-centered care.

Developed in partnership with:



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Compassionate engagement strategies include providers being able to take these six steps for compassionate action when families and other caregivers are distressed:

1. Notice – Be present in the moment and able to recognize signs of distress in families.
2. Self-check – Be aware of our emotional connections to our past and our initial judgments (cognitive appraisals). Appraisals are natural and dependent on your frame of reference from your experience and “training” and are often not accurate or complete.
3. Seek to understand – Suspend appraisals. Listen to understand the concerns/distress from the other’s perspective. Move towards generous interpretations of another’s behavior.
4. Cultivate empathy – Genuine concern develops based on what we have come to understand. This leads to a growing desire and intention to help. Keep listening for understanding if empathy seems out of reach.
5. Discern best action – Work with the families to figure out what would actually be helpful to them rather than what you think would be helpful or was helpful to you in past, similar circumstances.
6. Take action – Be aware that intention alone is not compassionate action.

(Combined from works of Monica Worline, *Awakening Compassion at Work*, 2017 and Beth Lown, *The Schwartz Center for Compassionate Healthcare*, 2014)

SELF-CARE



STRATEGIES

Bringing It All Together Through My Hands – An activity to summarize compassion and self-compassion

1. **Please hold your hands out and squeeze them into fists** (hold for at least 30 seconds).
 - a. Explore how you feel, what emotions arise as you clench your fists?
 - b. Say how you feel out loud.
 - c. **This is a metaphor for self-criticism or resistance** – what it feels like when we fight with ourselves or our experience.
2. **Now, open your hands and turn your palms upward.**
 - a. Explore how you feel, what emotions arise?
 - b. Say how you feel out loud.
 - c. **This is a metaphor for mindfulness** – what it feels like when we are present and open to ourselves and our experiences.
3. **Now, extend your palms and your arms forward.**
 - a. How does this make you feel?
 - b. Say how you feel out loud.
 - c. **This is a metaphor for common humanity** – what it feels like when we reach beyond ourselves and include others. In our vulnerability we discover the common aspects of humanity and can form bonds with others.

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STRATEGIES

4. Now, place one hand in the other with both palms facing upward. Slowly bring them to your chest. Feel the warmth and gentle pressure. Breathe gently.
 - a. Reflect on your feelings with this last change.
 - b. Say how you feel out loud.
 - c. **This is a metaphor for self-kindness or self-compassion.** Caring for ourselves is the foundation that supports our mindful compassion for others and the avoidance of self-criticism and resistance to what we are experiencing. Self-compassion allows us to find comfort and strength in our common humanity.

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Activity:

Compassionate Connections with Families or Caregivers

1. Give an example of a challenging behavior by a family. (Select one that is relevant to what your staff have experienced.)
2. Ask staff to talk in pairs about their initial thoughts about the potential meaning of the behavior and how they would respond.
3. Have six different perspectives on the same family from different people in the family's life written on cards and ask each person to read their description to the group. Continue until all six perspectives are read.
4. Now ask the pairs to make any revisions in their planned response based on the broader perspective.
5. Discuss as a whole group. Did insight into the family change your response? How? What, if anything will you need/would like from others in or outside of the school to make a positive connection with this caregiver?



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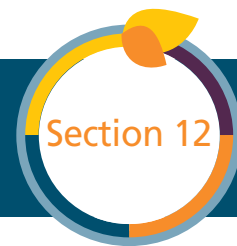
Staff Support



Circle Agenda

Circle Topic	CR Section 12: Building Compassion-Based Relationships with Families & Other Caregivers
<p>Planning</p>	<p>Send the introduction document from Section 12 in the online toolkit at least 4 days prior to the circle to all participants.</p> <p>Remind leadership of the following points:</p> <ol style="list-style-type: none"> 1. This section begins the wellness practices portion of the toolkit. Your participation in the conversations as a peer-learner for personal wellbeing will provide opportunity for you to make authentic and personal connections with the group. 2. The wellness sessions should give you insight into potential wellbeing supports that you can offer to all staff. <p>For the full leadership preparation document, please visit this page.</p>
<p>Purpose of Circle/ Learning Objectives</p>	<p>We are learning how to create collaborative relationships with families and other caregivers that enhance client supports and prevent compassion fatigue for both the family/caregiver and service provider.</p>
<p>Materials/ Preparation/Time</p>	<p>Time: 45-50 minutes</p> <p>Materials:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Circle kit <input type="checkbox"/> Values and shared agreements created in first session <input type="checkbox"/> Blank journaling paper <input type="checkbox"/> Writing utensils <input type="checkbox"/> Copies of the following for all participants: Compassionate Connections with Families or Caregivers of compassion when there is a challenge <p>Set-up: Up to 15 chairs arranged in a circle without furniture in the middle.</p> <p>To consider: Understanding Your Social Location as a Facilitator – Active Bystander Intervention: Training and Facilitation Guide.</p>

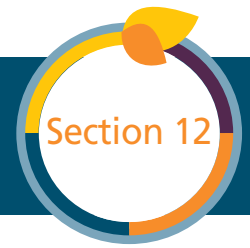
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Circle Topic	CR Section 12: Building Compassion-Based Relationships with Families & Other Caregivers
<p>Welcome/Check-In (5 minutes)</p>	<p>Successful health and human services provision is truly a team sport. Just as our own wellbeing is not dictated by our individual strengths or efforts, so too is the health and wellbeing of the people we serve. There are a multitude of players – from clients, families, service providers, organizational staff and leaders, and others in the community – and we must consider and engage with each these players to be effective and resilient in our own roles.</p> <p>(Go-around) Share a brief example of a positive interaction you had in the last week with one of the “players” mentioned in this quote.</p> <p>Explain: When it comes to the health and human services field, interacting with the families and other caregivers of the people you serve can be an integral part of your work.</p> <p>In the circle today, we will be talking about our relationships with these families and caregivers. And when we use the term caregiver, we are referring to parents, children, legal guardians, partners, friends, spouses, and whomever else may be a primary caregiver for an individual.</p>
<p>Mindful Grounding (5 minutes)</p>	<p>Putting self-check from Compassionate Action Steps into practice:</p> <p>Practice a grounding activity that can be used prior to meeting with a client’s family/caregiver. Select from any of the grounding activities from previous circle agendas.</p> <p>Bring to mind a client’s family or caregiver where you are struggling to build rapport. Consider the following beliefs adapted from the core concepts for client, family, and caregiver engagement as you picture this family or caregiver:</p> <ul style="list-style-type: none"> • Just like me, clients and their families/caregivers are worthy of respect and dignity. • Clients and their families/caregivers make the best decisions for themselves and their loved ones based on the information they have. • Clients have the right to define “family” and to determine how they will participate in care/services and decision-making. • The responsibility for cultivating and sustaining partnerships among health-related organizations, providers, caregivers, and community rests primarily with service providers and leaders.
<p>Guiding Questions (20 minutes)</p>	<ol style="list-style-type: none"> 1. (Go-around) Share an example of a challenging behavior by a family member of caregiver that you have experienced in your role at your agency or organization. (The facilitator should make a list of behaviors participants share out.) 2. (Go-around) What are some potential meanings behind any of the behaviors listed? What feelings are associated with those behaviors? (The facilitator should make a list of feeling words shared.) 3. Handout: Responding to Challenging Interactions with Families. (Give participants a couple minutes to read the article.) 4. (Individual Reflection) Go back to the challenging family or caregiver behavior you shared. Plan what you now think would be a helpful/compassionate response based on the perspectives shared in the circle and the reading.

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Circle Topic	CR Section 12: Building Compassion-Based Relationships with Families & Other Caregivers
Putting it into Practice (10 minutes)	(Go-around) What is one discovery or technique discussed today that will have a positive influence on your compassionate action with families or other caregivers?
Closing (5 minutes)	(Go-around) Share a word of gratitude based on your experience building compassion resilience with the group. Share quote with circle participants as a closing thought for your time together: <i>"Change will not come if we wait for some other person or some other time. We are the ones we've been waiting for. We are the change that we seek."</i> – Barack Obama

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Responding to Challenging Interactions with Families

Partnering with families in health care settings has been associated with improved clinical outcomes for clients and decreased stress for providers, but dealing with challenging family dynamics can also be a common source of stress for providers.

However, responding collaboratively to challenging family situations and maintaining a positive partnership can be made easier when appropriate skills and strategies are applied.

The following strategies have been adapted from Zaider et al.'s (2016) *Responding to challenging interactions with families: A training module for inpatient oncology nurses*. Read through each strategy and think of a time when either you have utilized it or could have utilized it to ease a tense or challenging situation in the past. **Consider role-playing or discussing each in pairs or as a group.**

1. Checking your emotional posture, encourages providers to become mindful of any emotional vigilance during an interaction with a family. The purpose of this strategy is to empower providers to pause and attend to their own stress so that they can respond skillfully. Providers are encouraged to rate their "emotional temperature" (1–10) and take steps to shift their stance from reactive to curious. The 3-minute Breathing Space (or any brief mindfulness strategy discussed in this toolkit) is an exercise drawn from Mindfulness-Based Stress Reduction programs that can be incorporated here as a simple tool for disengaging from the anxiety of a situation, witnessing it without judgment, and making a clear-minded choice about how to respond. Providers are encouraged to practice appreciative listening and slow down the natural impulse to problem-solve.

2. Becoming an ally to the family, emphasizes the benefits of acknowledging the multiple perspectives in a family. This is accomplished by eliciting each member's concerns, identifying overlap among stated concerns, highlighting positive intentions, and identifying aspects of the problem that the provider and family can unite around. Reinforcing the family's unique expertise is also encouraged as a means of aligning with the family and engaging them as a resource to each other and to the health care team.

3. Frame choices, describes ways to address differing perspectives between the family and provider, enabling the provider to maintain collaboration and support to the family. Providers are encouraged to be transparent with the family about what choices are available to them and the parameters of their role (e.g., expectations within the particular health care setting). This strategy emphasizes the importance of reinforcing the positive intentions of the provider, even when at variance with the family's wishes.

4. Respond empathically, involves acknowledging, validating, and normalizing sources of distress and/or mistakes made. Skills include normalizing the family's experiences, conveying that concerns are being taken seriously, and, when applicable, reframing anger as a dimension of worry and grief.

5. Block escalation if inevitable, recognizes those occasions when the provider or the family becomes too distressed to maintain constructive discussion, at which point facilitating a transition to a "timeout" with a clear plan to return is an encouraged solution.

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Communicating Difficult News to Clients and Their Families

When working with clients and their families, it can be challenging to effectively and compassionately communicate difficult news. The American Academy of Pediatrics, however, offers various, easy to remember, approaches to the challenge of entering into and maintaining a difficult conversation with a family that can be applied in various settings:

1. SPIKES

- a. **Set-up:** Consider privacy, who to include in the conversation, sitting down, and building rapport.
- b. **Perceive:** What is your understanding of the situation/issue? (Consider using the Ask-Tell-Ask strategy at right)
- c. **Invite:** Utilize a warning phrase such as “I’m so sorry, but I need to share some bad news with you...”
- d. **Knowledge:** Share knowledge using understandable language, give information in small pieces, and check in frequently.
- e. **Empathize:** As described throughout this toolkit, empathy is the ability to share in another’s emotions, thoughts, or feelings, and is crucial in providing quality, compassion care.
- f. **Summarize** and strategize with the client and family.

2. Ask-Tell-Ask

When deciding what and how much to share, a good place to begin is where the client and/or family are in their understanding. Ask-Tell-Ask is a way of making sure that they understand what you say.

- a. Ask the client/family member to describe their current understanding of the issue (e.g., Can you tell me what you understand of _____’s condition? What have the other providers been telling you about the situation?).
- b. Tell the client/family member in straightforward language what you need to communicate – be it bad news, treatment options, etc. Do not give a long lecture or a lot of detail. Provide information in short segments. Avoid jargon.
- c. Ask if the client/family member understood what you just said. Consider asking them to repeat in their own words, or ask them with whom they are going to share the news and what they are going to say to that person. Give them a chance to ask questions, so you can clarify.

Holding a Family Conference

When difficult situations arise, such as major changes in health status or new or complex needs or concerns, family conferences can be an important, yet sometimes daunting, process of engaging family members and providing compassionate, quality care. [This video](#) below offers 7 essential steps that can help you effectively and empathically inform, connect and make important decisions with clients and their families. And while this video takes place in a hospital setting, the steps can be beneficial to all health care providers in all settings when a family conference is appropriate, and can be adapted to conferences in which the client is an active participant.

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Reflection Worksheet

Family Engagement and the Stages of Change Model

Increasing your compassionate engagement with families is a goal to which the Stages of Change Model can offer insight and direction.

The Stages of Change Model of behavior change includes six well-defined stages that people move through as they work to change specific behaviors. When considering how the stages of change can give insight and support your current change goals, it is important to identify your current stage for a particular behavior change goal.

Part One – Assess Your Stage

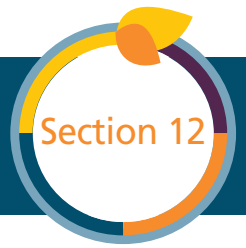
True	False	Check True or False for Each Statement
<input type="checkbox"/>	<input type="checkbox"/>	1. I improved my attitudes and behaviors around compassionate family engagement more than 6 months ago.
<input type="checkbox"/>	<input type="checkbox"/>	2. I improved my attitudes and behaviors around compassionate family engagement within the past 6 months.
<input type="checkbox"/>	<input type="checkbox"/>	3. I intend to take action in the next month and have already made a few small changes in my attitudes and behaviors around compassionate family engagement.
<input type="checkbox"/>	<input type="checkbox"/>	4. I intend to take action on my attitudes and behaviors around compassionate family engagement in the next 6 months.



Find the stage that corresponds to your responses:

- False for all four statements = **Precontemplation**
- True for statement 4, false for statements 1-3 = **Contemplation**
- True for statements 3 and 4, false for statements 1 and 2 = **Preparation**
- True for statement 2, false for statement 1 = **Action**
- True for statement 1 = **Maintenance** (if you are at this stage, select another target behavior)

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Part Two – Strategies for Your Stage of Change

Once you have identified your stage, go to that section and respond to the suggested reflection questions.

Precontemplation:

How might someone who cares about you and whom you respect, answer the following question? How have you noticed my defenses stopping me from hearing information from those who could be most helpful to me around compassionate family engagement?

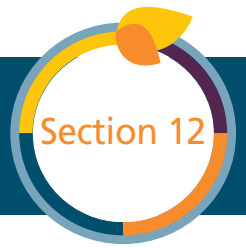
Who are the people in your life who you think offer the most positive influences? When was the last time you had a meaningful conversation with them about compassionate family engagement?

If you were going to make a positive change in how you engage with families, who might be the person in your life to push you to move too fast?

Who are two people in your life and/or community resources that you would benefit from being open to their insight and support if you wanted to make a change in how you engage with families?

Is there any behavior in your current approach to family engagement that, if you could free others who have the same behavior as yours, you would?

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Part Two – Strategies for Your Stage of Change *(continued)*

Contemplation:

What have been the impacts of your family engagement approaches to date? Who might help you discover answers to this question that may currently be hidden to you?

Make a list of all the pros and cons you can think of for changing how you think about and engage with families.

Pros:

Cons:

Take one of the cons of changing that behavior and write about why that con feels important to you. What is the story for you behind that con?

Research books, websites, people in your organization or community, etc. that would offer motivational stories that would encourage you to increase your compassionate engagement with families. After listing these, circle one that you are willing to expose yourself to in the next few weeks.

What seems to trigger the unhelpful past behavior?

What might be the consequences of and reactions to you changing that behavior from yourself and others? (What new image of yourself arises?)

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Part Two – Strategies for Your Stage of Change *(continued)*

Preparation:

What have you discovered that you would like to be a part of your plan of action to increase your compassionate engagement with families? List the steps of your plan and next to each give a time to start and a way that you will find support to do and maintain that aspect of your change. (Looking at the questions under Action may assist you to design your plan for change.)

Steps in my Plan	Timeline	Support
<p>You had reasons for the behavior that you have now chosen to stop or adjust. Think about the old reasons. Is the power of those reasons lessening now? Explain. (If not, you are still at the contemplating stage.)</p>		
<p>Go public. Who will you share your plan with? When?</p> <p>Name _____ Date _____</p> <p>What can that person do to support you in this change to more compassionate engagement with families?</p>		
<p>Who are others that you will share your plan with?</p> <p>Name _____ Date _____</p> <p>What can that person do to support you in this change?</p> <p>Name _____ Date _____</p> <p>What can that person do to support you in this change?</p>		

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Part Two – Strategies for Your Stage of Change *(continued)*

Action:

During the next three months, how will you refocus your energy in times that you would normally engage in the less helpful behavior?

What situations will you avoid that bring temptation?

What helpful reminders are you using?

What are you doing to keep yourself calm and focused? What positive means will you use to deal with pressure to return to less helpful attitudes and behaviors around family engagement?

How do you plan to recognize and free yourself from rigid thinking?

How have you practiced positive, realistic self-talk in relation to your plan for change?



Adopting a Strengths-Based Approach

Seeing the family as multi-faceted with lines of strength and support rather than problems and deficits is not minimizing risk, but placing it in context (Doolan, 2005).

A strengths-based approach operates on the assumption that all people, even if they are experiencing problems, have strengths and resources from which they can draw on to make positive change. A deficit-based approach, which focuses on what is wrong or missing, can overlook valuable skills and experiences a family has. It can also reduce a family's motivation to actively engage with providers and impair the likelihood of positive change for the client.

One important part of using a strengths-based approach to working with clients and their families begins with the language we use. The WI Office of Children's Mental Health put forward a guide (on page 2) that can help providers change the way they speak to respect and empower clients and families to work toward positive change.

Advancing Adult Compassion and Resilience: A Toolkit for Health Care Agencies | Section 12 | Building Compassion-Based Relationships

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Deficit-Based Language	Strength-Based, Recovery-Oriented, Person-First, Trauma-Informed Alternative
Describing a Person	
schizophrenic, a borderline, bipolar	person diagnosed with..., person who experiences the following..., in recovery from...
addict, junkie, substance abuser	person who uses substances; a person with substance use issues
consumer, patient, client	person in recovery, a person working on recovery, a person participating in services
frequent flyer, super utilizer	frequently uses services and supports, is resourceful, a good self-advocate, attempts to get needs met
Describing Behavior	
good / bad, right / wrong	different, diverse, unique
high- vs. low-functioning	doing well vs. needs supports
suffering from	person is experiencing, living with, working to recover from
acting-out, "having behaviors"	person's behaviors may indicate a trauma memory has been triggered, person is upset
attention-seeking	seeking to get needs met, seeking assistance to regulate
criminogenic, delinquent, dangerous	specify unsafe behavior, utilizing unsafe coping strategies
denial, unable to accept illness, lack of insight	person disagrees with diagnosis, person sees themselves in a
manipulative	strength based way. (Honor the individual's perception of self.)
oppositional, resistant,	resourceful, trying to get help, able to take control in a situation to get needs met, boundaries are unclear, trust in relationship has not been established
non-compliant, unmotivated	the constraints of the system don't meet the individual's needs, preferred options are not available, services and supports are not a fit for that person. (Assume that people do well if they can.)
DTO, DTS, GD (Danger to Others, Danger to Self, General Danger)	people should not be reduced to acronyms; describe behaviors that are threatening
entitled	person is aware of her/his rights, empowered
puts self and/or recovery at risk	person is trying new things that may have risks
weakness, deficits	barriers, needs, opportunity to develop skills
unrealistic	person has high expectations for self and recovery