How Do I Know When I Need HELP! What Might I Need?

When is My Help No Longer Enough? Where and What Then?

Key Elements & Risks

Three Elements:
- Safety
- Ability
- Engagement

Ratings:
- OK
- Risky
- Dangerous
In Real Life There are Many Pieces to the Puzzle

You & Your LIFE
The Person & Their Life
The Place - where they stay
The Support System
The Dementia & Other Health Concerns
The Monitoring System & Safety Net

Some Hints... About You

• You worry a lot
• You are tired & don’t sleep well
• Your emotions are getting the better of you
• You don’t ‘like’ the yourself or the person you are caring for
• You are neglecting other people or parts of your life
• You feel like the Lone Ranger
• You are using ‘BAD’ coping strategies – A LOT

Some Hints... About the Person

• Unhappy or upset most of the time
• Expressing feeling of paranoia or worry
• Getting more isolated & giving up life
• Clinging and demanding constant attention
• Refusing the help and assistance you offer and those you try to bring in to help
• Behaviors create high risk for injury, problems, or complications
Some Hints… About the Place

• You can’t control ‘safety’ – access, use, availability
• You can’t monitor performance well enough
• There have already been ‘incidents’
• Others are at risk – spouse, children, neighbors…
• Location, location, location….
• Demands of the setting EXCEED the skills of the person

Some Hints … About the Support System

• There isn’t one
• It is saying ‘no more’
• There are ‘call outs’ OR ‘no call – no show’
• It is NOT matching the needs – medical conditions are getting worse or there are episodes
• There have been multiple ‘issues’ or ‘concerns’ raised – multiple times

Some Hints… About Abilities

• It is inconsistent – everyone will see it differently
• It can hide at times (MD visits, driving evals, out of town visits, authority figures around)
• Hope for the BEST, BUT Plan for the Worst
• It will surprise you!
• It is the hardest caregiving there is!
• It will change… usually when you are not ready!
The More You Learn
the Better You can Help
&
Make Decisions that Work!

So… what’s happening to them?

• Memory damage
  – Can’t learn new things
  – Forgets immediate past
  – Does time & space travel
  – Uses old memories like new
  – May not ID self or others correctly
  – CONFLABULATES
  – Follows visual cues
  – Seeks out the familiar
  – Can get stuck on an old emotional memory track

• Language damage
  – Has very concrete understanding of words
  – Misses 1 our of 4 words – may miss “Don’t…”
  – Word finding problems
  – Word salad problems
  – COVERS
  – Follows your cues
  – Gets very vague & repeats
  – Uses automatic responses
  – Mis-speaks

So… what’s happening to them?

• Impulse Control Problems
  – Say whatever they are thinking
  – Swear easily
  – Use sex words or racial slurs when stressed
  – Act impulsively
  – Not think thru consequences
  – Can’t hold back on thoughts or actions
  – Responds quickly & strongly to perceived threats
  – Flight, fight, flight

• Performance Problems
  – Thinks they can do better than they can
  – Can sometimes DO BETTER under pressure – sometimes worse
  – Uses old habits
  – Attempts can be dangerous or fatal
  – They will tell you one thing and then do another...
  – Families may over or under ‘limit’ activities
Positive Progression

GEMS...

Sapphires
Diamonds
Emeralds
Ambers
Rubies
Pearls

Seeing What is Possible - GEMS...

Sapphires – True Blue – Slower BUT Fine
Diamonds – Repeats & Routines, Cutting
Emeralds – Going – Time Travel – Where?
Ambers – In the moment - Sensations
Rubies – Stop & Go – No Fine Control
Pearls – Hidden in a Shell - Immobile

Believe -

People with changes
Are doing
The BEST they can!
AND SO ARE YOU!
What shouldn’t we do???

• Argue
• Tell ‘WHOPPERS’ – that relate to emotions
• Ignore problem behaviors
• Try a possible solution only once
• Give up
• Let them do whatever they want to
• Force them to do it

So WHAT should we do???

Deal with OUR Stress & Distress
Remember who has the healthy brain!

Two Time Frames to Consider

Right Now
&
The Future
Right Now

• What is happening that is OK?
• What is happening that is NOT OK?
• What is NOT happening that needs to?
• Set some priorities – separately – THEN together
• Keep what works
• Decide on TOP NEEDS to CHANGE
• Start on it – ONE STEP at a TIME!

Care Partners...

• Be a partner, not a boss
• Be an advocate, build a team
• Do with me, not for me or to me...
• Learn the ‘SO WHAT?’ philosophy...
• Learn to let go not give up
• Learn what you are good at, & what not...
• These ideas are for you TOO!

Keep Alert...

• Evaluate...
• How is it going...?
  – What’s working?
  – What’s not working?
• Is it time to change?
  – Dementia is progressive
  – Activities will need to change
• It’s about letting go NOT giving up...
In the Future...

OR if things are past earliest stages when you are starting on the journey

You Will Want People Who Know About...

- Resources
- Environments
- Care skills
- Dementias
- Other conditions & ability changes
- Activities & how to Fill the day
- Places and people in your location
- When it’s time to...

Support - Who Will...

- Help manage health care
- Deal with legal issues
- Help manage $$
- Help manage housing
- Arrange schedules
- Help manage food/meals
- Monitor/manage meds
- Communicate with friends/family/others
- Deal with crises
- Help with IADLs
- Help with ADLs
- Fill the day – things to do
- Help at night
- Stay at the hospital
- Look at care options
- Monitor helpers
- Be friends
- Transport
- Support the care partner
What is Person-Centered Care?

Combination of...
• Person's wants
• Person's needs
• Still can do
• Can’t do
• Can do with support
• Individual good
• Common good
• Family needs
• Family wants

Balanced with...
• Caregiver skills
• Caregiver availability
• Private space
• Public space
• People resources
• Equipment resources
• Safety & Security
• Rules & regulations
• Others needs and wants

Who Needs to Buy In?

• The person
• The care partner
• Family members
• Friends and community members
• Service providers & agency personnel
• Medical advisors – MDs, RNs, etc
• Financial supporters
• EVERYONE Involved!

Think about YOUR relationship with the person....
Your Relationship

• What is your history?
• Who had what roles?
• Who else was involved?
• Who else might you act like, look like, or sound like?
• What is changing? How much?

If there are areas for concern or mismatches, you may need...

• Someone to do what doesn’t work
• Someone to support you
• Someone to relieve you
• Someone to lead you
• Someone to take turns with you
• Someone you pay or support
• A WHOLE TEAM of folks to help
• ADVISORS who know about....

So WHAT should we do???

• Remember who has the healthy brain
• Use your healthy brain
• Be willing to change your -
  – approach – words
  – routine – actions
  – habits – plans
  – ‘rules’ – beliefs
  – arrangements – environment
How to Decide What Must Be Taken Over...

• How to keep the ‘role’ but take over key activities that are critical—safety wise
  – Driving
  – Cooking
  – Finances
  – Shopping

• Advance PLANNING is the KEY...
  – Durable HC POA
  – Durable $ POA
  – Talking about it BEFORE it is happening... “what if...”
  – Consulting experts & asking for help
  – Provide options
  – Reduce ‘cues’
  – Do other things...

How to Figure Out if IT is WORKING....

• You are feeling better
• There are fewer ‘fights’
• There is less distress
• You have money
• The problem behavior is reduced or stopped
• The ‘new relationship’ is working for you and the other people you love

How to FEEL OK...

• Get spiritual support
• Get intellectual support
• Get physical support
• Get social support
• Get expert help, if needed to do tasks
• Take breaks
• Pat yourself on the back
• Think of the alternative...
Believe in Yourself

- Acknowledge your skills and talents
- Recognize your limitations
- Explore what is needed
- Look for the matches
- Identify the missing pieces
- Decide on what to do
- Decide on what NOT to do
- Get help for what is needed
- Be *GOOD* to yourself!

So When Should You Say WHEN!

- Cost versus benefit – life not money
- What is possible VERSUS what is PROBABLE
- Best Case Outcome – Is it worth it?
- Big Picture for the person
- What did they tell you before?
- Who are they... are they still able to be that person?
- Is this about them or about you or about someone else???

What Support Do Various GEMS Need?

- **Sapphire** – will depend on physical – episodic
- **Diamond** – weekly-daily check in & monitoring
- **Emerald** – daily to hourly support, programming, & monitoring
- **Amber** – minute to minute support, environmental management, & safety checks
- **Ruby** – eyes & ears on, physical help
- **Pearl** – 24/7 monitoring & support – total help
### How to Know When it is Time for a Move?

<table>
<thead>
<tr>
<th>Factors</th>
<th>Home</th>
<th>Home with Help</th>
<th>Supportive Living</th>
<th>Memory Specific Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safety</td>
<td>No safety issues at the home and the surrounding community; residents have been assessed and assessed for risk (treatment)</td>
<td>No incident has occurred and there are no existing physical supports and care planning that are adequate for current conditions</td>
<td>No incident has occurred and no concerns have been identified; physical supports and available monitoring are adequate for current conditions</td>
<td>Suitable and secure environment is comfortable and safe for improved monitoring and response times</td>
</tr>
<tr>
<td>Ability</td>
<td>Able to take care for all personal and care needs—no help is needed</td>
<td>Person is walking with the help of one or more caretakers to complete all required tasks and routines</td>
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<td>Person can use the guidance and experience to participate in both care and daily life, as the interventions improve quality of life and the environment</td>
</tr>
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<td>Engagement</td>
<td>Engaged in community, family, and staff routines or engagement activities</td>
<td>Engaged in community and at home; and involved in activities outside the environment, mostly make use of things as they are needed</td>
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</table>

#### Safety

- **Some safety concerns have been identified in the home and in the surrounding community; residents have been assessed for risk (treatment).**

  - Help is being given or support is needed, but it is not a regular and routine part of their care. The person does not need help to meet their needs, and they are not at risk of injury or harm.

  - People who are not engaged in daily activities outside the environment, and they have no interaction with their surroundings, may be at risk for injury or harm.

#### Ability

- **The person can get around and engage in most of their needs and routines, but they have been or are seeking changes that are concerning.**

  - People who are not engaged in daily activities outside the environment, and they have no interaction with their surroundings, may be at risk for injury or harm.

- **The person does not have enough ability, support, and resources to engage in daily activities outside the environment, and they are seeking changes that are concerning.**

  - People who are not engaged in daily activities outside the environment, and they have no interaction with their surroundings, may be at risk for injury or harm.

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#### Engagement

- **Engaged in community, family, and staff routines or engagement activities.**

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Supportive Environments:

Include Two Factors:

- What you \textit{like}
- What's \textit{good} for you

Supportive Environments

The 3 Positive P's

- Physical Environment
- People—the ways they act and respond
- Programming

The Supportive Sensory Environment:

- What You Hear
- What You See
- What You Smell/Taste
- What You Feel
So, What Do We Do?

Thank you for joining!

For more information, contact:

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