

## **Five Types of Health Support for People Living with Dementia**

*by Teepa Snow, MS, OTR/L, FAOTA*

We typically do NOT spend a lot of time considering which form of health care we should be seeking or getting for ourselves when we are healthy and well. If we get acutely ill, of course, we would get ourselves treated. When we are well, we may typically say we want to try to reduce our risks of getting a chronic disease or hastening the onset of possible health problems. But of course, we rarely actually follow through on doing all that we can to reduce those risks; it is too much trouble, too costly, too extreme, too poorly researched to verify the value. In other words, it seems like too much work for the possibility of benefits. As part of our lack of attention to this situation, we do NOT complete our advance directives and discuss them with the person we think will be our durable health care power of attorney (our surrogate decision maker) while we are well and whole. And even if we do a bit of that, we keep it global and really don't look seriously about our genetic codes and life-style risks.

Here is my list of possible approaches to health care:

- Preventive – keep something from happening
- Curative – get something to stop happening and return to previous level of function and health
- Restorative – regain some abilities after an event/episode/illness that changed abilities, through the use of rehabilitation and compensatory strategies
- Maintenance – keep something from getting worse, although getting better is not really an option
- Palliative – provide support and comfort although the condition or illness is progressing

Each of these is unique in its focus and techniques to be used. Each has a role and place in our care and well-being, but no one single approach can really meet our needs throughout our life and throughout the course of any long term illness.

If some form of dementia kicks into gear, everything we think and know about what we should be doing and who should be doing it will be called into question. Suddenly, we can become hyper-vigilant or aggressive in our approaches. We can turn into zealots, or brutal task masters in our efforts to not leave any stone unturned and to do all that we can do to try to help. It is also possible that some health care providers, when finding the diagnosis is dementia, immediately jump into late stage care considerations, although the person is still in the early stages of the condition. Rarely, do we step back and consider the range of health care alternatives. Rarer still is our interest in thinking them through carefully to determine what makes sense at any point in time and in planning for the probabilities of the future. This support table makes an attempt to lay out five options for approaching health care. Each is unique and has a place in our lives. The question is complex, but which one is the right one for you and the person you are supporting, at which stages of change, and how will you know that?

I have also provided a few resources that are out there to help you begin to explore what you might want to consider FIRST for yourself, and THEN with the person living with dementia. Some of the resources have been posted by people living with dementia and they represent their

perspective and point of view. Others are provided by agencies or organizations devoted to helping people retain control over their life as it changes due to an acute event, a chronic or progressive illness, or a terminal condition. Since dementia involves all these situations, it gets complicated. All the more reason to talk about it BEFORE it becomes a crisis or surprises us. Take the time to consider what you think and want before you enter the emotionally charged atmosphere of a hospital emergency room, a doctor's office, a rehabilitation center, a nursing home, an assisted living location, memory care place, or hospice support. Advance planning allows us time to work through options rather than get stuck with what is offered without considering the past, present, and future for the person and ourselves.

As we start a new year, perhaps it is time to look at what we are doing and determine whether it is really what our partner would want, and that makes a difference. Maybe it is an opportunity to pull the team together and talk it through. Talking about what is possible can ultimately help us to determine what is the better course of action, given the full picture of where we have been, where we are, and where we are headed. The good thing about thinking ahead is there will be time to reconsider as things change.

Types of support	Message	Actions – examples	GEMS® states
<b>Prevention</b>	<p>Use strategies that keep something from happening</p> <p>In the world of dementia this means reduce the risk, not prevent it from happening</p> <p>It must be balanced with the stress or distress of changing habits and routines of a lifetime and building desires for specific pleasures and needs</p>	<p>Eat healthy – reduce processed foods, reduce sugar, increase omega 3 fats, drop omega 6 fatty intake, more fresh vegetables and fruits, Mediterranean diet</p> <p>Get 7-9 hours of sleep – get sleep apnea and sleep problems treated</p> <p>Stay cognitively active – learning new things and doing new things</p> <p>Exercise aerobically at least 150 min a week</p> <p>Keep cortisol levels in the lower-normal range</p> <p>Use safe sexual practices to reduce risk of sexually transmitted diseases</p> <p>Take medications only as prescribed and report negative impact or side effects or lack of results immediately</p> <p>Manage finances in such a way as to ensure they will provide the support needed at present and over time</p> <p>Manage relationships in a way that will preserve them or develop relationships that are healthy</p> <p>Hydrate well and often – include the possibility of cranberry juice to reduce risk of UTIs</p> <p>Get flu vaccines</p>	<p>Sapphire – health promotion is critical to well-being</p> <p>Diamond – changes may require major amounts of support – must be perceived as mutually beneficial to attempt</p> <p>Emerald – balance of what is good for the person and what the person will tolerate and want</p> <p>Amber – some, not all, things should be considered based on life time patterns, sensory experiences and tolerances, as well as value to quality of life for those in the immediate world of the person</p> <p>Ruby – many things should be considered carefully regarding value versus intolerance or stress</p> <p>Pearl – almost all of the decisions should reflect a combination of advance directives that have been established, open and frequent discussions about value versus cost to the person and those in the world of the person, and long-term impact as dementia advances into the late stage</p>

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<b>Curative</b>	Use techniques and strategies to fix the problem – make it like it was before the injury or insult. The goal of these interventions is to make the problem go away to return to life as usual – pre-insult or injury. Usually fairly short term in duration (surgery, medications, treatments)	Infection treatment – medications like antibiotics, anti-virals Rehydration after dehydration Nourishment after mal-nourishment External fracture repair (casting) Soft tissue treatments after injury – icing, heat, immobilization, elevation Wound healing – combo treatments to heal pressure areas or infected sites Surgical intervention to remove the problem (remove an appendix, remove tumors or growths) Radiation or chemical treatments that cure the problem/condition	Sapphire – typically helpful Diamond – should be strongly considered Emerald – should be considered, if the process/treatment can be monitored and managed – pain management and activity management will be needed Amber – pros and cons and all options should be discussed prior to doing something Ruby – as acute episodes of illness are repeated with increasing frequency, the value of repeated treatments should be carefully considered based on advance directives and overall health and wellness, open conversations about these topics are most valuable if they are held prior to getting into this GEMS state Pearl – any curative measure should be very carefully considered in light of the person's advance directives and quality of continued life if the intervention is attempted. Careful consideration of assessments and testing should be evaluated prior to automatically doing it, based on possible or probable outcomes and the comfort and well-being of the person during and after the risk is taken

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<b>Restorative</b>	Working after an event or condition has begun to re-establish a baseline or regaining of abilities, function, or performance level through the use of environmental supports, training programs, new routines, and assistive devices and personnel	Rehabilitation programs developed and offered by professionals to regain lost or reduced function by either improving performance or using compensatory devices or strategies, such as: <ul style="list-style-type: none"> <li>• Post fracture or repair programs</li> <li>• Surgery recovery programs – after MI, stroke, MVA, etc.</li> <li>• Episodic programs to improve function during the course of progressive chronic health conditions – Parkinsons, COPD, ADOM, Arthritis, TB, CHF, etc.</li> <li>• Environmental and task modification to promote abilities by changing access, use-ability, or safety supports</li> <li>• Training of support personnel to integrate the modifications into daily routines and programs that reinforce the new actions/performance</li> </ul>	<p>Sapphire – careful discussion regarding willingness and interest in using and making the modification a part of daily routines and new habits should be considered prior to investing heavily in this approach with Sapphires and Diamonds</p> <p>Diamond – additionally with Diamonds, the value of the change should be revisited and agreed upon repeatedly in order to get the new changes to become part of daily routines. An additional support person will typically be needed early and often to obtain gains and sustain them when Diamonds are involved due to reduced executive abilities combined with immediate recall and new learning limitations</p> <p>Emerald – relationships are the critical piece of engaging Emeralds successfully in restorative programs. Managing discomfort and stress while offering support and pleasure is vital to get rehearsals of the new patterns. Creating activities that have value and meaning for the Emerald will foster performance and willingness to do activities. Safety systems to reduce the risk of use of old routines, habits, devices, and systems will also need to be part of any successful plan</p> <p>Amber – this approach will have limited impact as the Amber will be driven toward engagement in activities and experiences that provide pleasure and away from things that are negative or adverse. The only programs that will be successful will involve ones that combine a positive interaction/activity with acknowledgement of discomfort or the negative for short periods of time only, surrounded by positive experiences, so that</p>

<b>Restorative (cont'd)</b>			<p>emotional memories are more positive than negative. Typically equipment and devices will only be used if the support personnel initiate their use each and every time they are to be used and careful and creative monitoring is part of the plan</p> <p>Ruby – Taking the time to determine realistic goals and possibilities is critical for Ruby restoration programs. Looking back at the person's interests, abilities, and patterns prior to the event or change can guide the selection of what to offer, how to offer it, where to do it, when to do it, and who to involve so that gains made can be integrated into routines that can be sustained. Creating opportunities that use preserved gross motor skills and acknowledge loss of fine motor and complex language or task comprehension will typically promote better outcomes</p> <p>Pearl – Any effort to restore function must be weighed against the discomfort or distress it might cause. The decision to modify a task or situation will require support from the primary providers of care and support, or it will be something that is not integrated into daily patterns after the skilled intervention. Having team agreement prior to trying out an intervention and having all parties actively involved in assessing the value throughout is key for longer term usefulness</p>
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<b>Maintenance</b>	Working to keep function and activity at current/existing levels. No gain in ability is expected, but efforts to optimize and sustain abilities are the focus ( <i>Use it or lose it</i> is the primary reason for keeping engagements with activities, people, and the world the same)	<p>Activities that are used are designed to encourage continued participation and use of skills and abilities as they currently exist. There is no improvement expected, but there is an awareness that not doing something results in reduced abilities over time.</p> <ul style="list-style-type: none"> <li>- Exercise programs geared at keeping mobile, balance, strong, flexible</li> <li>- Eating programs to keep weight, body fat, glucose levels, hypertension, fluid and electrolytes, cholesterol , and muscle mass stable</li> <li>- Sleep programs to keep wake/sleep patterns as they are</li> <li>- Stress management programs to keep BP, BS, pain, pulse, and respiration static</li> <li>- Activity programs to keep brain activity and abilities at current levels</li> <li>- Social engagement opportunities to keep interaction skills operating</li> <li>- Spiritual practices that sustain existing levels of faith</li> </ul>	<p>Sapphires – typically done after reaching a level of ability or function that seems to be a good match for the person or after a new level of ability is established</p> <p>Diamonds – due to changes in memory, impulse control, and reasoning it is possible that desire to sustain may exceed ability to implement without major supportive considerations. Guilt and frustration may be common findings as the effort to do what one should do is challenged by the inability to keep it up over time without major effort</p> <p>Emerald – daily routines and rituals that support abilities can typically be implemented at this time in the condition as long as there are many pleasurable moments or events built into the daily pattern. The challenge typically is more for those supporting the person as the repetitive nature of the routine and desire for even more repeats can be wearing and boring</p> <p>Amber – the primary effort to sustain function will probably go into being flexible about trying to get the person to do something on a regular schedule. The care providers will need to have a system of keeping track of whether or not something has been done that day/cycle, as tasks and activities may need to be approached multiple times in order to get the desired engagement. Additionally, there will be some tasks that are not desired by the person, but seen as essential to continued health and well-being (bathing, grooming, toileting, oral care) that will require new skills and approaches from support personnel, increasing their stress levels</p>

<b>Maintenance (cont'd)</b>			<p>Ruby – sustaining gross movement patterns and active efforts to interact and engage are a major focus for the Ruby state. The challenge is in rethinking activities and engagements that rely on dexterity, integrated visual skills, talented mobility, verbal comprehension, or production. Using vocalizations, big movements, music, rhythm, and life-long patterns can help keep life going for as long as possible, however frequent re-assessment will be needed to determine if it is still working or if change is occurring in existing abilities. There will come a time when sustaining is no longer the goal or even an option (hydration, muscle mass, respiration, suck-swallow, chewing, walking, transfers, day/night awareness, etc.</p> <p>Pearl – maintaining even the basics will become challenging and then impossible during the Pearl state. The challenging part is determining which changes are caused by acute conditions that can be altered and which are symptoms of system failure and overall depletion and represent an ending of physical existence. Indicators of changes that signal progression are often repeated and return even once treatment is successful at first</p>
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<b>Palliative</b>	Comfort and support is the focus. There is an acknowledgement that life cannot be sustained or maintained as it was before and that it is time to let go of the physical body. Life is ending and the goal is to have the transition be as comfortable, stress-free, and pain-free as the person is able to be	Care routines change focus to promoting a sense of well-being and relief of discomfort or distress based on the person's desires combined with the care system's ability to be supportive. During entry into active dying patterns, it will be vital to have someone familiar with both the dying process and advanced dementia on hand to provide the support needed for the person and their immediate care team/family. Not everyone in the last stages of dementia goes through this experience with pain, not everyone does it in a smooth and un-interrupted time frame. Some forms of dementia, such as Lewy Body dementia can advance and retreat multiple times over a period of time, prior to entering the true final process. It helps if the care support personnel are all on the same page as the person is actively dying	<p>Sapphire – it is rare for someone to continue with Sapphire abilities into the final phases of life. It is very possible that the person may shift to another GEMS state. It is also possible that at moments, when someone with severe cognitive loss is dying, their cognition may be clear and bright for moments. In those Sapphire moments, active support as it is requested can be offered as it makes sense for overall comfort</p> <p>Diamond – Offering support and comfort in the following order: spiritual, emotional, and then physical comfort is important to Diamonds. Diamonds may need authority figures to offer support and permission to move on or let go.</p> <p>Emerald – Interests, focus, and abilities can fluctuate rapidly if the person is entering an end of life stage while also living in episodes of their life. Knowing the person's life story and emotional and intellectual background will be important in determining how to offer comfort and support that will work as the person may <i>time-and-place travel</i> extensively during this period</p> <p>Amber – Determining what is comforting and what is distressing can be a huge challenge at this point. Needs and tolerances can change in seconds and can be extreme. Offering comfort will be effortful and may require additional support personnel with skills and knowledge. The use of medications that limit mobility and interaction skills can be useful to those surrounding the personnel for a break, but evidence is lacking as to their impact on the person</p>

<b>Palliative (cont'd)</b>			<p>Ruby – careful monitoring and recognition of what indicates comfort and distress is less easy to determine for people surrounding someone in a Ruby state. There may be a trial and error period needed to determine what seems to work and what does not. Frequent changes in position, activity, or opportunities may alternate with long periods of disengagement and somnolence or rest-less disengagement</p> <p>Pearl – as the end of life approaches, it is very likely that someone in a Pearl state will spend more and more time disengaged and resting with only very short windows of alertness or arousal. As systems begin to stop functioning, it is possible that longtime care routines will need to be revisited and altered (moistening lips only, no drinking), tastes of flavors only (not eating), shifting positions only slightly (no turning), washing only selected body parts (bathing, etc.). Ensuring that all conversation continues to acknowledge the person's presence in all speech and comments will provide comfort both to the person and to those who have known the person through their lives. Finally, it may be important to consider offering the person time alone as well as time with others to respect the possibility that the person will only be able to leave this life if there is no one they are leaving behind in their intimate or personal space at the time of their going</p>
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## Additional Resources

[The need for integrated versus fragmented health care](#)

[Integrating palliative care into dementia care](#)

[Advance directives – Five Wishes](#)

[An approach to considering the option of palliative care rather than traditional curative or restorative care more reasonably](#)

[Michael Ellenbogen, living with early stage Alzheimers, speaks to his advanced directive regarding thickened liquids](#)

[Posting on the importance of considering palliative care versus curative care for pressure sores in selected situations](#)

[This tutorial looks at the continuum of care options for someone unfamiliar with the array of service and terms](#)

[Comparison of curative versus palliative care models](#)

[Nursing home residents with advance dementia dying in facilities – what is known](#)

[Alzheimers Association paper on End of Life Decisions](#)