

What Do You Do for FUN?

What Gives you Joy? by Teepa Snow, MS, OTR/L, FAOTA

Try this out and see what it does for you. It's a video with animals that talk as though they are human.

https://www.youtube.com/watch?v=EQ1HKCYJM5U

Did you laugh? Smile? Chuckle? Did you call someone else over to watch? Or did you think it was silly or stupid? With humor it is pretty much to each his or her own, but there are some joys that are more universal. What's the value in laughing or finding moments of joy in a day? It is essential to survival and helps to keep us well and whole.

Here is a question and possibly a challenge for you. Think back over the past day, the last 24 hours of your life, and come up with a list of things you looked at, listened to, said, did, smelled, or tasted that gave you pleasure, made you smile or laugh, or filled you with joy. Make a list, then consider how much of your time they filled. Compare this list and time quantity to what you have done over the past day that was challenging or stressful, made you work, used your energy, or made you sad or frustrated. How about comparing your fun time to the time spent just resting or sleeping? Consider how much time you used during that period taking care of your body's needs (bathing, dressing and undressing, grooming, eating and drinking, toileting, taking medications or vitamins, and taking care of your home, and getting where you needed to go and back). If you are like most of us, you typically don't even think about this time, it just gets done when you can fit it in; yet putting it off or not doing what your body needs can move it from business as usual to stressful and unpleasant time and experiences. Having too many unmet intimate needs results in a sense of tension and pressure, making it hard to find joy as well as becoming more needy and less able to tolerate changes, surprises, or challenges.

So, how about doing the same thing for someone living with the brain changes that come with dementia. As abilities are impacted, we add one more category of activity, when the care partner is providing supervisory or physical support to the person living with dementia. It's called *wait time*. Time spent by the person waiting for the helper to provide what is needed or wanted.

Each of us fills our lives with a variety of activities designed to create a balance and sense of wellbeing and health. One of the four categories is *play*, also known as leisure or recreational activities. The purpose and value of this time is to provide us with pleasure, reward, and satisfaction. These activities release endorphins and dopamine. Even serotonin has a role to play as does adrenalin. Without these moments in our life we begin to sink into a funk and experience sadness, depression, or even despair. There is evidence that prolonged absence of these moments can profoundly affect us and may push us to attempt to find pleasure in unsafe or unhealthy ways in order to get a quick fix of feeling good.

Humans are designed to seek and desire joyful experiences to thrive and survive. Deep in our core, we must find moments of pleasure and satisfaction to continue to live and live well. The length of the experience is not as vital as the occurrence. Here is a list of one website's recommendations and thoughts about possible ways to encourage the release of endorphins.

http://www.wikihow.com/Release-Endorphins

Much of the seeking seems to be triggered by the right amygdala. The pleasure seeker. Let's look at three levels of pleasure seeking:

We all have *likes*, things or experiences we like or prefer over others. They give us a sense of happiness or satisfaction.

When we are exposed to things and experiences that are hard or challenge us, we have essentially had to cope with or deal with experiences or activities we don't like that irritate us. In other words our left amygdala has gotten into the act. We are a little irritated, annoyed, anxious, worried, and frazzled. When this happens we have to work to keep our cool, do our job, and get through it. Once we finish, we are driven a little harder to find some pleasure and joy to counteract the stressful feelings and effort we expended. Now we **want** some pleasure, and we want it now. Immediate gratification! When these urges hit us, we are in strong seek mode and may ignore possible risk or warning signals or possible concern to get the relief we believe and feel is important at that time. In some cases we want a little extra or push a little harder, and become less aware of how others are experiencing our presence and behavior. On the other hand, we may be so tuned into getting pleasure from a relationship that we forgo opportunities for wellness, future goals, larger picture agendas, or long-term objectives that we have set for ourselves.

If by any chance we continue to not get our pleasure center satisfied we are living with high and persistent stress or distress. We don't allow ourselves the time to find joy and pleasure in doses that fulfill us in healthful and regular ways. Our primitive brain becomes insistent. It is registering a lack of happiness and pleasure. It believes we are at an immediate risk of not surviving without getting some pleasure. It sends out emergency signals. I must have pleasure to survive. I need relief, the lack of joy is killing me. I am threatened, I must get something, do something, go somewhere, find someone that can immediately give me what I need or I will surely die.

Unfortunately, for some people, once they find unhealthy substitutes for healthy satisfactions and pleasures, they can develop physiological and psychological dependencies or addictions. Most of us are well aware of and tuned in on drug addiction, alcohol dependency, nicotine issues, as well as gambling and sexual addictions. What we may not consider, is some of the other chemical addictions and dependencies that may be more common among care partners or someone living with a changing brain. Do any of these patterns sound familiar?

- drinking cup after cup of caffeine in order to get awake or stay awake,

- eating large quantities a little at a time of salty, sugary, or crunchy/chewy snacks,
- shopping and buying items that are not useful and frequently ignored even though the purchase is problematic for finances and relationships,
- spending more and more time or money on line or with an app just to see if you can do better next time,
- getting repeatedly injured while trying to exercise, engage in a sport, or exhilarating activity and yet continuing to do it, or
- spending time with a person or people who encourage our pleasure-seeking, risky, or dangerous behaviors in order to feel good.

The bottom line is that if we do not find activities and experience that gives us pleasure in quantities that are adequate to sustain us on a regular basis, we will begin to seek it in risky or dangerous ways, or give up and want it all be done. This is true for all members of the care team and for those we support who are living with the brain changes that come with various forms of dementia. Without fun in our days, we can rapidly become needy and used to seeking unhealthy quick fixes or unhealthy substitutes to those things and experiences that we can use to meet these pleasure seeking requirements.

Take a look back at your list of how you are spending your time, as well as time spent by your partner. When, where, what, and how are you getting pleasure or having fun? How much and what forms are you using? Consider a few options and alternatives that provide a variety of possible pleasurable experiences.

Solo activities that are passive. These are things that stimulate one or more of your senses, but for which you do nothing active in order to experience. Possible actions might be to watch, listen, smell, think, pray, and/or read. These activities do provide potential for pleasure, but they are not the most rewarding if there is little else happening in your day and can create tension and stress if they trigger a sense of loneliness, boredom, non-participation, or loss.

Group activities that are passive. These offerings combine a sensory experience with a social experience. They provide a potential for fellowship and friendship as well as potential to use retained social chit chat skills and automatic social skills to connect and share in simple and pleasurable ways. Examples of these activities might include attending a concert or other musical activity, going to a game or sporting event or watching one on a big screen, going to a museum or art gallery or program, attending an educational program with a speaker who knows how to use visual, auditory, and rhythm in their program, or going to a performance or play with music or a joyful theme.

Solo activities that use gross movement and action. The purpose of these forms of play encourage cardiovascular activity and can help to release endorphins, without an absolute need for high degrees of skill or effort. These activities can typically be graded or modified in a variety of ways to allow for changing abilities, without eliminating their beneficial effect. Examples of these activities might include: walking, swimming, swinging, rocking, running, pushing a loaded cart or weighted stroller while completing

errands or shopping, tai chi or yoga, stair climbing, drilling on parts of favored sports, or moving to music on your own.

Group activities that use gross movement and action. The value of these types of activities is that you use communication, sensory, and movement systems. These activities provide us with huge benefits in endorphin potential. If we can control social anxiety and match up our comfort needs with these types of offerings we can get real bang for the buck. Some possibilities include, dancing with a partner, singing in a choir, group walk outs or runs, sports that may or may not be competitive, pet or animal engagement (walks, throw and retrieve, or toy play), gardening with friends or family, child or baby play and games (London Bridge, Ring-Around-the-Rosie, etc.), or being active in a club or team that practices and works out together toward a common goal on a routine basis. On a personal note, thanks to my friend, Lauren, I got a stimulating roller coaster ride in Vegas; that was joyful, if a little extreme. My endorphins were off the charts after many long hard days of work. I would never have done it on my own, but to please her, I took the ride and we both had a ball.

Solo activities that use eye-hand skills or require fine-motor skill in mouths, fingers, eyes, and toes. These activities, when modified for the person, can provide the just right challenge to allow the thrill of success, the joy of achievement, and the excitement of completion. Depending on personal preference, it is important to consider if there is more need for process or product. Which matters more; doing it or having an outcome? Depending on the answer to this question, these activities should be altered to provide that which is more sought after and valued. Examples might include: fixing a dessert for the family or friends, building a sandcastle, playing a game of solitaire, working on or completing a jigsaw puzzle, painting or coloring, sorting or organizing, or using apps or programs to play a game on the computer or internet. It is important to consider a little caution in the category, as it can also become an area of frustration or isolation as situations change and abilities are altered. These are meant to be part of the day, not become the only way of finding pleasure. These activities can easily become a gateway into the use of negative coping strategies and activities that are amygdala driven due to a sense of unmet needs. Because they are done solo, it is possible that changes in ability and sense of pleasure is not accurately rated or compared to the sense of frustration of loss. Changing gears and altering what is being done may not happen without structure and guidance from a trusted source.

Group activities that use eye-hand skills or require fine-motor skill in mouths, fingers, eyes, and toes. These activities can include table top games or activities, team sports that are more skill-based versus relying on big movement or strength, craft programs or classes, group discussions of things seen or done, group outings or travels, gatherings to participate and share common interests such as painting, bird watching, flower identification, animal rescue or care, or child or baby care.

So where are you with finding joy in each day? What is good about it, what is not, and where can you start to build joy into the equation? Start small but steady and build your play time with your partner or individually. Consider taking baby steps to be the change you wish to see. A little joy can spark an avalanche. Get the ball rolling or consider the possibility that you need help to get this bucket filled and reach out. Anyway we can, I

believe we must seek positive and powerful ways to find joy for ourselves and those we seek to serve. Just try making a joyful noise, someone might just sing or join in! You won't know what is possible and what might happen until you give it a try.