

FSHD Wellness Group Gathering (on Zoom)

Monday, July 8, 2024

- *Life brings change. Life would be boring if it didn't encompass change. Yet the changes that FSHD brings to us are more intense than most—if not all—of us would voluntarily choose.*
- *Adjusting to life with FSHD is an ongoing process. In some ways it helps us better face the eventuality most people experience in their later years: aging. Except the combination of FSHD + aging presents new and uncertain realities.*
- *As individuals living with the unpredictable progression of a FSHD diagnosis, we learn (sometimes easily and other times not so easily) to embrace adaption and flexibility.*
- *While FSHD may not affect a small number of us very much as we grow older, it is more likely that we will become aware of the impact of physical limitations in our day to day life **much sooner** than other people living without similar health problems.*
- *These days, “aging in place” is being promoted more and more. For those of us with FSHD, is this a realistic choice? If yes, how do we plan ahead and what things can we do now (or fairly soon) to prepare to age well with FSHD?*
- *Planning ahead and thinking of our future needs is a good thing to do. However, our future options depend on our individual situations which can vary greatly. We need to remember this and be gentle with ourselves if our personal situation differs from others living with FSHD.*

July's Wellness topic, “Aging in Place—-Planning & Preparing” was an excellent resource to help us face this stage of life with FSHD.

[Note: Much of this month's presentation was applicable to anyone with FSHD who is experiencing significant progression at younger ages.]

Following a warm welcome by June Kinoshita to everyone attending our July Wellness Zoom meeting, a group member introduced our two guest presenters.

Hailey Conway and **Sam Koemel** are co-owners of the **In Home Preferred Company** in Indianapolis, Indiana. They met while attending the University of Indianapolis and both women graduated with Master degrees in Gerontology and Doctorate degrees in Occupational Therapy.

They then worked as occupational therapists at in-patient rehabilitation settings with adult patients (many were seniors) recovering from significant health conditions, surgeries, and/or injuries. They observed that several of these people were being discharged home to settings that posed serious accessibility challenges.

Hailey and Sam recognized a definite need for services to bridge this gap to enable people to return to safer home environments. They decided to do course work which qualified them to be Certified Aging in Place (CAIP) specialists. Following that, they founded their new business which offers home consultations and assessments; recommendations for modifications/renovations; and can also include overseeing the contractor(s) doing the modification/renovation work.

Hailey and Sam shared their definition of aging in place as “living in one’s home safely, independently, and comfortably regardless of age, income and ability level”. They then described the initial step of a consultation—taking time to discuss the client’s **specific needs and hopes related to aging in place safely and holistically and realistically.**

Hailey and Sam provided many pertinent points related to aging and the future. **They encouraged us to each take adequate time to think of our specific circumstances and wishes for our future.**

Listed below are many points which they include when dialoguing with a client before focusing on and providing actual adaptation or renovation suggestions. Each person’s answers (to the queries listed below) will vary as none of us can predict our personal FSHD progression nor other age related changes that may arise. Hailey & Sam emphasized that **it is valuable to prepare for our futures by taking stock and looking ahead.**

LOOK AHEAD & CONSIDER . . . what would be the benefits (and challenges) for me to remain in my current living situation?

Benefits: autonomy . . . independence . . . routine . . . familiarity . . . comfort . . . possibly cost effective . . . likely have a support network available . . . less disruptive (ie compared to a move)
Challenges: fall risks (dependent on home layout) . . . need for renovations . . . upkeep and maintenance . . . isolation (physical and social) . . . possible transportation problems if unable to drive . . .

LOOK AHEAD AT MY VALUES & PRIORITIES . . . looking forward, what are my values and priorities and goals as I age?

Continuing to work . . . full time or part time . . . do I want to (or will I need to) retrain . . . or consider switching to a different job . . . when to retire . . . when I do retire, what leisure activities or courses would I like to do and/or learn . . . is there a hobby I’d like to focus on . . . what volunteer opportunities are available in my area . . . what is on my “bucket list” . . . relationships—do I want to be near family and/or friends . . .

LOOK AHEAD AT OPTIONS AVAILABLE . . . in terms of locale/location; housing choices; availability of support/help; medical care; financial resources; grocery shopping and meal preparation; transportation choices; socializing opportunities etc.

“Aging in place” doesn’t mean we have to stay in our current housing or locale (be it rural or urban) . . . it may be that moving to a more accessible abode will be more practical . . . how much practical and emotional support do I currently have (supportive friends and/or family members) . . . should I consider moving to a more weather friendly location (to avoid winter ice, snow and cold) . . . if a move is possibly needed, should I move now, later, or when I can no longer manage on my own . . . are there hands-on practical caregiving choices in my current community or where I might move to (if that type of help is needed now or in the future) . . . are there adequate medical resources available nearby (ie hospitals, doctors, specialists, other medical professionals) . . .

LOOK AHEAD REALISTICALLY . . . *is my current living situation (be it a house, cabin, mobile home, condo or apartment etc) “age-friendly” (especially knowing about likely FSHD progression) . . . can I continue to maintain my home and yard or will I need to pay others to look after those tasks . . . will I be able to continue driving until the end of my days . . . if not, how would that impact my ability to grocery shop and get to appointments . . . what alternate transportation options are available . . .*

LOOK AHEAD & ASK QUESTIONS . . . *this may involve seeking people who have training and work experience to help us evaluate all of the above . . . additionally, we will need to continue drawing on our own experiences of adapting to the changes which FSHD brings . . .*

Onto the practicalities of “aging in place” . . .

Few homes were built to incorporate future accessibility needs as part of the house design. In fact, Hailey and Sam shared that about 90% of US homes would require some modifications to be ADA compliant & only 1% of current housing stock is considered fully accessible.

They provided several steps to include as part of the process to age-in-place well:

1. Have regular health check ups! Follow medical recommendations including life style suggestions. They reminded us that falls occur in 1 of 4 adults aged 65+ causing injury and even death. Being pro-active with our health care is important.
2. Do a tour of your own home space noting hazards and potential concerns—family members or friends may also have some input to share! (List these points and share with professionals mentioned in #3, #4 and #5 below.
3. Arrange for an ****occupational therapist**** (one who specializes in home assessments) to do an in-home visit. OT’s are trained and experienced to quickly evaluate problems in home set ups. Additionally they are often aware of a wide variety of solutions!
4. If you own your home and therefore are responsible for ongoing maintenance and long term replacement of capital items (furnace, roof, flooring, siding, appliances, plumbing etc) it is helpful to be aware of those types of expenses in addition to any accessibility/modification costs.
5. In that regard, it may be good to hire a qualified home inspection service to ascertain any additional specifics of future home repairs (that may not be visible to our eyes). Their report should include a time-line, cost projections, and practical suggestions related to the needed work.
6. Both OT’s and house inspectors may know of other people (construction/tradespeople) who provide modification type renovations to create better home accessibility.
7. When hiring anyone to do such work, check their qualifications, training, references, insurance, business license etc.

[Note: ****As part of a home assessment, an OT will also take time to learn about a person—-their work background, activities and interests; family; medical history (including current diagnosis & long term prognosis); allergies; any dietary limitations; medications; mobility and other health related devices being used; an overview of ADL’s (activities of daily living); support services being utilized etc. They will usually do some basic visual and hearing screening and possibly some basic cognitive testing. Often the topic of driving will also be discussed.]

Hailey and Sam then shared some practicalities:

What features does a basic age-friendly accessible home have?

- *flat smooth outdoor walkways are less of a tripping hazard than gravel, brick or tile surfaces*
- *level entry/exits ie no stairs & no threshold steps*

- a built-to-code ramp if there are outside steps (any steps should have railings on both sides) [ramps need to be 12" in length for each inch of height required]
- enough room in driveway or garage for people to get in /out of vehicle safely; retrieve mobility aids such as canes/crutches & walkers; transfer from scooter or wheelchair in/out of car
- ideally a bedroom and adapted/accessible bathroom on main floor (or potential for future conversion of a family room or den etc that could create one level living space)
- if a one level re-design isn't possible, consider if a chair lift or elevator is feasible to access upstairs bedroom spaces and bathroom(s) on that level too

What inside features help create a safe, accessible home?

- no-step transitions into rooms (to reduce tripping hazards)
- wider doorways and adequate space for a (future) wheelchair to turn especially in kitchen, bathroom and bedroom / pocket doors and/or barn doors may add more width to a doorway
- A walk in or wheel in shower is important
- preferably no loose rugs (again, a tripping hazard) or carpeting (more effort needed to move with a rollator/walkers or with a manual wheelchair; carpets need more upkeep (especially if a power scooter or wheelchair are being used)
- furniture layout may need to be changed so there's enough space for mobility aids (and to prevent falls) / purchasing more practical furniture (if needed)
- consider our "reaching limits" when organizing items / keep frequently used items within reachable spaces
- gradually downsizing one's possessions is easier than leaving it until we have less ability to do so!
- reducing clutter reduces fall risk plus less "stuff" is easier to look after!
- easy access to storage (ie drawers rather than lower cabinets in kitchen)
- wheelchair accessible counters
- walk or wheel in pantry with open shelving is a nice feature
- light switches and thermostats within easy reach
- placement of small appliances (ie convection toaster oven /microwave / air fryer / slow cooker etc) on countertops for ease of use & to limit oven use (when leaning in to take out a hot dish becomes unsafe)
- roll in shower(s), higher height toilet(s), grab bars, and wheel under bathroom sinks
- accessible laundry appliances with space available for a rollator/walker or wheelchair if such is being used
- smoke and carbon dioxide detectors / fire extinguishers
- have a plan in place for emergency exiting / escape route
- At the end of their presentation, Hailey and Sam **re-iterated the value of being pro-active as we look ahead to our future housing needs.** They shared some questions to consider when evaluating our current living situation and assessing our future needs:

1. Is it practical and feasible to stay in our current home? Can we afford needed renovations and adaptations and do we have the stamina to live alongside the upheaval of having the work done?
2. Do we need to look for a home that is more accessible and/or has less upkeep and maintenance (inside and outside)?
3. Should we consider moving to a different house / condo / apartment with a better layout?
4. Would we have the financial resources (and energy) to have a new home built that would be better suited to "aging in place"?
5. Do we anticipate needing more help and support in the future? What care resources are available in our current location? Would an option be to move closer to family members or supportive friends?
6. While not discussed directly, moving to supportive housing (ie independent living with supports or assisted living) offers health care services may be an option due to changing medical circumstances of ourselves or our partners/spouses. Not all independent or assisted living situations will meet our physical limitations . . . if considering this form of housing as an option, it will be important to evaluate such options specific to our needs.

7. Don't overlook financial grants and programs that may be available to help cover the costs of needed renovations / adaptations. Check out what is available in your area.

Finally, Hailey and Sam encouraged us to gather all this information together to create an open-ended plan to help us better "age in place"! Obviously this plan can be reviewed and revisited as changes occur in the future.

Thank you so much to Hailey and Sam for their very informative presentation! Also, thanks to the group member who recommended them as speakers for today's topic.

[This member also shared with us about the help which Hailey and Sam provided in his housing decision journey/move.]

Some comments (arranged in very random order) from the group discussion following Hailey's & Sue's presentation:

- If getting on and off bed is difficult, take off legs or remove frame so mattress is at a better height
- Look online at bed rail choices—using a bed rail is energy saving and reduces fall risk
- Have an easy to access low light source available if needing to get up in the dark

- Use a shower chair with side arms when showering / a hand held shower, grab bars or a support pole are practical aids to use
- Someone has a sturdy tall walker (with high area rests) and uses that while showering
- Dry off as much as possible before transferring out of shower / one person wears socks with grip (on the bottom) to move between shower and a seat / to conserve energy and reduce fall risk, sit (as much as possible) while drying off and dressing etc
- Have someone assist with showers/baths if your balance is not steady

- Another tripping hazard: consider putting **pets** in another room (with door closed or crate them) when doing activities that could cause you to lose balance if they suddenly get underfoot

- Walkers, rollators and wheelchairs don't do well on carpet. Choosing a very low pile or flat type carpet is preferable. It's recommended to use carpet tape to keep rugs from sliding. Ideally it's better to choose non-carpet / low slip flooring . . .

- Kitchen counters can be designed to have knee space under them to accommodate someone using a wheelchair

- Research technological assistance aids such as Alexa or Siri that can make life easier for us!

- Look online for products and ideas that are available to help us safely "age in place"

Resources and Websites (from the Meeting Presentation & Discussion)

1. Hailey Conway's & Sam Koemel's business website: < inhomepreferred.com >
2. National Association of Home Builders (NAHB): < www.nahb.org >

[click on: NAHB Community; then Directories; then Local Associations; then your state]
OR
[do a search for “finding an aging in place specialist” or “accessibility features”]

There are several articles on this website / three pertinent ones are:

1. Aging in Place Remodelling Checklist
2. Make Your Home Safe for All Ages
3. A Case Study: An Occupational Therapist & Remodeller Partnership Leads to Client Satisfaction

3. FSHD Society Radio with Tim Hollenback

Twice a month interviews available to view on FSHD Society’s Radio YouTube channel:
[Search for FSHD Society Radio YouTube & include topic title below]

Two sessions related to Aging in Place:

1. Feb. 2024: Jane Nemke of Designs to Thrive
2. Dr. C. Farmakidis: Adapting Your Home for Safety (19-28 minutes)

4. Search for FSHD Connect Classroom (2020): Creating an Accessible Home with Karen Pitsley

5. FSHD Society Blog (June 10, 2019): “Universal Design” is Smart Design by Jane Earl

6. SeniorResource.com has a few shorter articles that relate to aging in place.

7. Muscular Dystrophy Association’s quarterly QUEST magazine also has several articles. Look online to access the following interesting / helpful reads:

1. QUEST 2023, Issue 2, pg 28: Budget Friendly Home Mods
2. QUEST 2022, Issue 2, pg. 20: Smart Homes New Story
3. QUEST 2023, Issue 2, pg. 34: Think Ahead: A Place of One’s Own
4. QUEST 2024, Issue 2, pg. 28: Common Good: Universal Design
5. QUEST 2017, April 16, 2017: Accessible Living
6. QUEST 2015, July 16, 2015: Home, Sweet Modified Home

Finally, last but definitely not least, go to QUEST 2024, Issue 3 (August 13, 2024) featuring one of our own—Ranae Beeker! This is an excellent article [6 Tips for Living Well as a Senior With a Neuromuscular Disease]. The end of the article includes several more links to pertinent aging-in-place information & resources. Be sure to read this article in the current issue of QUEST!

