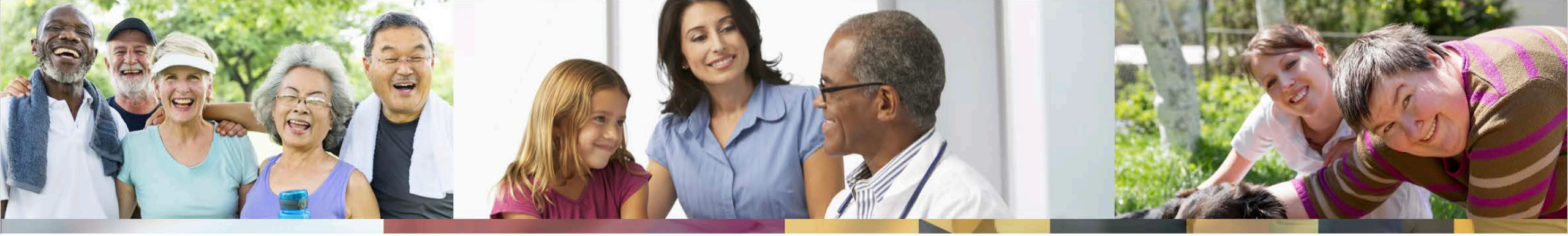

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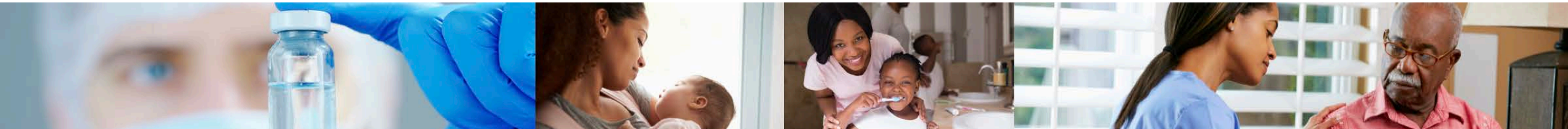
Developing One Page Profiles for Support in the COVID-19 Health Care Setting

Anastasia Edmonston MS CRC MD Traumatic Brain Injury Partner Project Coordinator

2021



THANK YOU!

Maryland Department of Aging

&

Michael Smull and colleagues at the Learning Community for Person Centered Practices and Support Development Associates for their support in the creation and use of materials for today's presentation

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What we will cover today….

The one page profile is a quick summary of what is important to and for individuals and how they can be supported by those around them, professionals, family members and friends

- How to use the one page profile, a Person Centered discovery tool with people living with brain injury during the Covid-19 epidemic
- Supporting each other in isolation-Choices among constraints
- Controlling what we can, supports and accommodations for the present and beyond

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Over the past few months there have been changes and challenges…

- To our physical health
- To our routines
- To our work and families

Behavioral Health issues can emerge, or become worse such as anxiety and depression. The two most common mental health issues. There are concerns in general regarding the use of substances to cope with these challenging times due to the isolation we are experiencing as we abide by our states' guidance to "flatten the curve"

For Older Adults and People Living with Disabilities & their supporters, the Covid-19 virus presents many challenges including:

- Access to services and supports: routine medical care and blood work, rehabilitation services, behavioral health care, personal care, support groups and transportation
- Loss of jobs and the benefits that come with employment
- Concern for the health of loved ones

In general, a lack of structure and a predictable routine is essential for most of us, if we are living with challenges due to conditions with associated cognitive impairments there may be a steeper learning curve regarding the "new normal"

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Examples of 1 Page Profiles-Pre-Covid-19

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One-Page Profile-Jean

Jean loves:

- Getting her nails done and picking out earrings and bracelets to wear
- Her hair cut in a short style
- Cats, chocolate and her grandchildren

People love Jean because:

- She cares about others
- Is a good friend
- Well respected oncology nurse, always a resource to others

It is important to Jean that staff:

- Honor her nursing career and experience
- Give her a heads up so she knows what to expect before any thing happens in her room or to her in the course of providing care — this helps manage her anxiety

Jean's story

She grew up in Malden, MA. She spent her summers in Northern Vermont with her beloved aunts and uncles.

She and her husband of 45 years, Jim, moved to Connecticut as newlyweds. They raised four kids and have four grandchildren.

She is a proud Democrat.

She and Jim are very active in their church.

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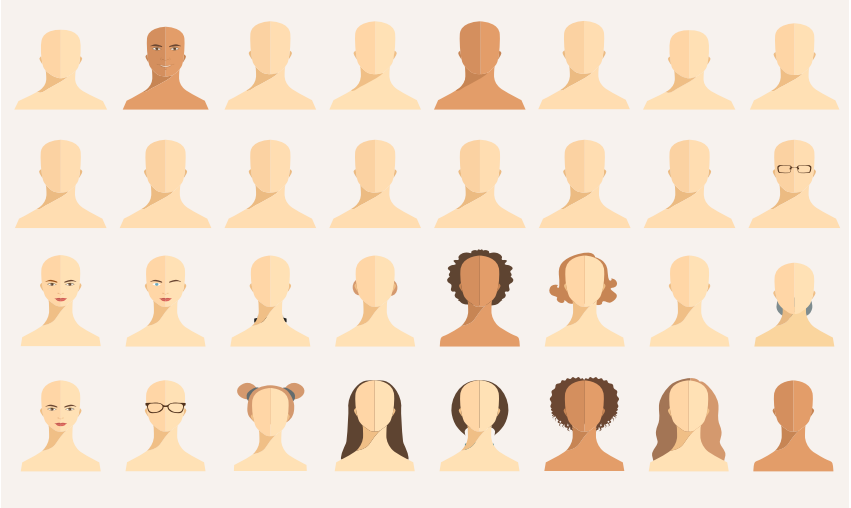
One-Page Profile-Pat

What people like and admire about Pat:

- Dependable
- Honest
- Friendly
- Takes care of their dad



What is important to Pat:

- Family and Friends
- Being a valued (and long standing employee)
- Time playing games on devices
- Attending church
- Being independent in the community (learning new bus routes as needed)

Supports Pat needs to stay happy, healthy, and safe in the community and on the job:

- Know what to expect for the work week, schedule, who the shift supervisors will be etc.
- Know that their dad is well taken care of when they are at work
- Be able to run situations by their employment specialist so they can think before they act

For a good match, characteristics needed to be present or absent in paid supporter:

- Patient and kind
- “Really takes the time to get to know me and my dad”
- “ I hate sports like football & baseball, love Japanese anime”
- Honest—”I don’t understand why I am feeling/acting angry sometimes”
- Reliable for the long-term (it is hard to “break in” new staff)

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Developing a One Page Profile for Covid-19 Health Care Settings

Michael Smull

The Learning Community for Person Centered Practices & Support Development Associates

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Begin with questions…

- Where is the 1 page profile going to be used, what is the context?
- What do you want people to learn from reading the 1 page profile?
- What do you want people to do with the learning?

Remember

- If no one reads it
- If no one uses it
- It was a wasted effort

The context is a covid-19 health care setting.

- What do we know about the settings?
  - Staff are very busy, may be overwhelmed
  - They want to provide the best care in the time they have
  - They are very interested helping patients feel less anxious, more comfortable

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How Creating a 1-Page Profile can Help Hospital Staff Deliver Person Centered Care

"The most intense experience in fighting Covid-19 for me is bearing witness to what true bedside manner and health care looks like despite fear.

When my co-workers get into the rooms and talk with the patients, it's like the virus doesn't exist. ***We joke. We laugh. We talk about their families****."*

Kayla Sudduth, E.R. Technician, New Bedford, Mass
From The New York Times on-line story, In Harm's Way
https://www.nytimes.com/interactive/2020/world/coronavirus-health-care-workers.html#item-kayla-sudduth

Retrieved May 13, 2020

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What will work?

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Sam is severely hearing impaired. Speak loudly and slowly and make sure he can see your mouth

Sam's 1 Page Profile

What you may like and admire about Sam

He always wants to help others before he takes care of himself

He is a jokester.

He loves his family and friends

What's important to Sam about his support while in hospital …

- Calls from and to each of his kids (Tina, Dixie)
- Tina R., 555-555-5555, daughter, HCPOA
- -Dixie D., 444-444-4444, daughter.
- His connections with his kids
- Sam's phone and charger are on the bedside table.
- Tina and Dixie are Emergency Contacts 1 and 2

Things you can do to best support Sam as you care for him…

- Has feeding tube, distract him when assisting with the feeding tube.
- Tell Sam what is going to happen before you touch him or administer care…he may strike if startled.
- Call Tina if Sam becomes agitated.
- Distract Sam with conversation about feeding birds or growing plants when administering meds or therapies.
- Chocolate pudding or chocolate ice cream helps with swallowing pills.

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Josie

What people like and admire about me

- Devoted mother & grandmother
- Church & community volunteer
- Retired labor & delivery nurse
- Optimistic & good natured

What's important to me

- Positivity
- To be informed of my condition, don't keep things from me (my daughter Jolene is my durable power of attorney for healthcare)
- Having communion or praying with a chaplain when possible
- Not having pain
- Using oxygen all the time, even in the shower to manage my COPD

How to best support me

- Apply lip balm, hold my hand, let me know I'm not alone.
- Call me "Josie", not "Josephine", not "Mrs. Colvin"
- Place a cup of ice chips within reach throughout the day
- Wrap a sheet or blanket around the pillow to prevent sweating
- Ask me about my family or nursing career, it helps me feel like I matter and makes me less afraid
- Give me medication to help with pain, even if it makes me drowsy

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Martin's One Page Profile in a Healthcare Setting

What people appreciate about me

What people appreciate about Martin

- Great sense of humor
- Smart – quick learner
- Courageous and determined
- Observant

How to best support me

- Make sure is phone is charged and accessible, help him call Mom
- If he is upset, ask him if he wants to talk with Mario (555-555-5555) and help him call
- Ignore his speech impairment
  - Talk with him as a peer
- Ask don't order. Tell him what will happen before it happens, explain while it is happening
- Make sure his walker is in reach if it is OK to get out of bed
- No lectures

This one page profile was developed by Mario Gomez (agency director) with Marty's participation

What is important to me

What is important to Martin in the covid health care setting

- His family, daily conversations with Mom (777-777-7777)
- Not being told to stop smoking
- Coffee and energy drinks as he wants
- Watching/talking sports
  - 49ers, Cubs, Warriors
- Listening to Christian rock

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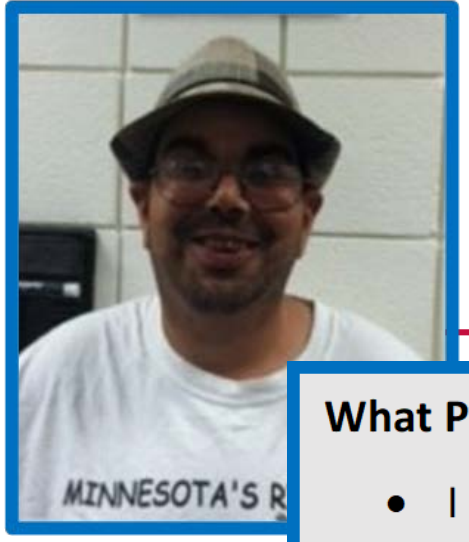

What People Like and Admire About Me

- I am kind and gentle person
- I make everyone feel welcome
- I know what I want in life and will "grab life by the horns" to get it.
- Great speaker/presenter

How to best support me

- I am a smoker and I may need a nicotine patch
- I recently had all my teeth pulled. Soft foods work best. I like a lot of flavor.
- Be honest while talking to me about my condition, tell me what you are doing and why. Ted will help me make decisions.
- I move slowly and get out of breath easy. If you want me to do something tell me and give me time to do it.
- Tell me jokes and make me laugh
- When I get down in the dumps remind me how far I have come and why I want to work hard to get better. Help me remember the positives.
    - I have my own apartment
    - I have a job I love
    - I am engaged and getting married – ask me about it.
    - I am great at sports

What is important to me

- To be respected and asked about what I would like.
- Talking to Holly everyday (555) 555-5555
- Having Ted (my guardian) to help me with tough decisions in my life (444) 444-4444
- Talking to family and my friend Andrew – having my phone close by
- Having a large pop (Mountain Dew or Pepsi) close by always

To make Joanne's stay in hospital go well …

What's important to Joanne about her support while in the hospital …

- Feeling in control. Being included in making decisions about her care
- Hearing information about her medical status (even if you don't think she'll understand much)
- That carers tell her what they are doing, why, and details (like her O2 levels, BP numbers, etc)
- Having her questions answered (even though you may have already answered them)
- That her son Sheldon (Ph: 987.654.3210) is kept informed and consulted on important medical information and decisions
- Having her rosary and prayer book within easy reach

Things you can do to best support Joanne as you care for her …

- Make sure she is wearing her hearing aids or speak loudly to her. But don't sound 'angry-loud'
- Keep questions to her simple. Ask just one question at a time, or else she may get confused
- Her memory gets worse when she's stressed. Keeping things as calm as possible helps much
- She has chronic anxiety. If she seems "out of sorts" or panicked, put your hand gently but firmly on her arm and say "Joanne….STOP!" That usually brings her around quickly. Then help her refocus on what you need her to do.
- When she seems anxious, ask her if she wants her rosary or prayer book. Those help her calm and bring her comfort.

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Getting Started

- Review the questions
- Who knows the answers to all of the questions? Whose input do you need?
  - Can the person whose profile it is answer all the questions? Do you need others to assist?
- If others, who? Family members? Close friends? Care givers?
- Who can tell you what others like and admire?

What Do Others Like, Admire, or Appreciate about Me?

- What are you good at, proud of?
- What do people praise you for?
- What do people say your good qualities are?

What is important to you?

- Who do you need to stay in contact with and what is the best way to do that - their phone numbers or email
- What helps you feel better when you are sick or upset
- What helps you wind down, relax, or sleep
- List any spiritual practices that help you feel grounded
- What helps you feel valued and respected

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What Does Good Support Look Like?

- Describe how staff can help you feel less anxious or uncomfortable, or calm or safe
- Describe the best way for staff to communicate with you
- Outline how staff can help prepare you for procedures, tests, and changes in care

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What Does Good Support Look Like?

- Explain how you might express pain
- Include how you prefer to take medications
- Include any physical or environmental accommodations you might need
- Describe any tips that might help staff help you

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Review your notes
Write a first draft

- Look for the 4, 5, or 6 most important things for staff to know for each section
- Use simple, plain language
- Keep the statements brief – complete thoughts, not necessarily complete sentences
- When it is done, read it out loud - it should take no more than a minute

Share, edit, add a photo

- Share the 1st draft with the person and those they choose to share it with in their life
- Get feedback and edit based on the feedback
- Add missing information but don't make it too long
- Add a photo (if possible)
- Print it so that it is 1 page with the one page profile

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TIPS

- In the Hospital –
  - Post it where it will be seen (over the bed, on the closet door, also request it is placed in front of the medical chart)
  - Make sure it moves with the person (people may be moved multiple times)

TIPS

- Improve the one page description-
  - Ask the person who helps the best and why
  - Ask those providing care to note any new learning (e.g. preferred positioning, music played
    - If there are phone updates on status – ask
    - Leave space to write on the template

Tips for Individuals and Their Supporters

- Can be done for and with family members, not just for older adults and individuals living with disabilities
- Care givers and providers in any home and community base setting, can be done one on one or in small groups with peers, caregivers and support staff
- Create on a device (laptop, IPad) or if preferred create a paper version, have several blank templates to create and refine the profile, laminate or put in a plastic page protector
- Choose an example of a completed 1 Page Profile as a model to refer to while creating your own or helping another person to create their own
- Feel free to update over time, nothing is written in stone!

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Why Creating a 1 Page Profile is Important for Older Adults and Individuals Living with Disabilities

- Gives people and their loved ones a measure of control in a time of uncertainty
- Allows for thinking through what are critical supports for the individual and how can they be applied in the hospital setting for example for cognitive and physical challenges related to dementia and other disabilities

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Examples of Functional Challenges for…

- Dementia
  - Memory, especially for new information
  - Impulse Control or Emotional Dysregulation
  - Physical challenges as the disease progresses such as with walking, swallowing, management of bowel and bladder

- Disabilities (Including intellectual & developmental)
  - Memory
  - Academic
  - Problem solving
  - Difficulty observing and following (often unspoken) social rules and norms
  - Poor judgement/impulse control
  - Difficulty with discerning cause and effect
  - Physical challenges, including but not limited to the areas of : vision, hearing, motor skills and coordination, speech and communication

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Examples of Strategies that can be Included in the 1 Page Profile

Memory/Thinking Skills	Impulse Control/Emotional Dysregulation
• Please tell me your name every time you come to provide care, even if you were here 5 minutes ago • Even though I do have trouble with learning or concentrating, don't talk over or down to me, address me directly even if one of my family members or supporters are on the phone/facetime etc. (or in the hospital setting with me in a non-Covid setting)	• No surprises please, give me a heads up and talk me through procedures such as blood draws, please explain why you are doing what you are doing • If I am going to move rooms or units, let me know as early on as possible so I can get used to the idea, it is hard for me to leave places and people I have become used to (and fond of!!)
Allow my family to provide a large wall calendar, cross off the days (with me or for me depending on how I am feeling) talk to me about specials days like family member's birthdays and holidays as they occur	• Please don't take it personally if I yell at you or say something that is insensitive, it is okay to redirect me onto another topic and/or say how my words affect you. • Remind me and help me to use my strategies for calming down (meditation app, counting to 10, deep breathing)
You may need to remind me, especially when I am tired, feeling really down or anxious, why I am in the hospital	Please help me to call my (family member, friend, clergy, therapist, peer support) when I am feeling agitated

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Examples of Strategies That can be Included in the 1 Page Profile - Physical

- I am living with weakness on one side of my body, I will need help with my positioning in the bed
- I have a splint I need to wear on my left hand at night to keep it from contracting uncomfortably
- If I am able to walk, please make sure my straight cane, walker or quad cane is within reach, my balance isn't what it used to be
- I have visual problems, I need written information provided to me in large print/make sure I have my glasses nearby
- I have some difficulty with bowel and bladder control, please make sure I am cued to use/assisted in getting to the bathroom/bedpan every 2-3 hours
- If I am able to feed myself, let me, but also provide a towel to drape down my front to prevent any dropped food from getting in the bed/on my pajamas
- Because of my deafness, I need hearing aids/the services of an interpreter/write things in my notebook/gesture and make sure I can see you lips when you speak to me

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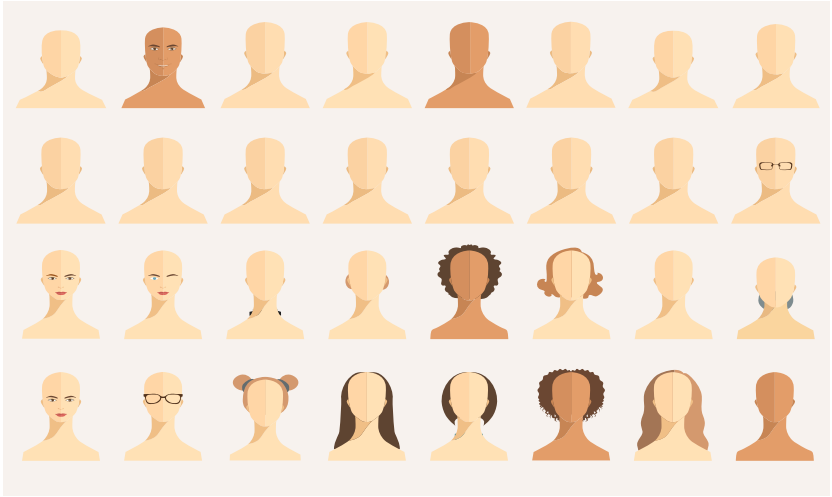
One-Page Profile-Pat-for the Covid-19 Health Care Setting

What people like and admire about <u>Pat</u>:

- Dependable
- Honest
- Friendly
- Takes care of their dad



What is important to <u>Pat</u> while in the hospital:

- Face time conversations with their father and employment specialist
- Time playing games on devices, keep devices by the bed
- Attending church on line
- Have pictures of family in the room

How to best support Pat while they are in the hospital

- They will feel less anxious if they know what to expect from the health care professionals, what is being done and why
- Assure them that their dad is well taken care of while they are in the hospital
- Make sure the hospital staff know that sometimes they loose their temper, and it usually because they don't understand something, not because they are mad
- If this happens, staff can repeat any new information verbally and writing it down in their notebook is a good idea as well

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Stasia's One Page Profile

What you may like & admire about Stasia

- With her husband Mark, raised two smart, kind daughters
- Animal lover, especially Desmond (dog), Squealers, and Cowboy (cats) & grand cats, Callie & Cosmo
- Friendly
- Loyal friend
- Loves her work in the field of brain injury services

What is important to Stasia while she is in the hospital

- She hates being kept in the dark, it will make her anxiety worse, keep her informed throughout her hospital stay about the treatments recommended and her progress
- Keep her husband & young adult daughters equally informed
- It is VERY important to her that her veganism be honored, no animal based food (includes dairy and Jell-O) of any kind. One exception is **bananas**, she is allergic to them

Things you can do to best Support Stasia while you care for her

- Keep her cell phone & glasses nearby, loves podcasts!
- Don't let her hair get "straggly"
- She loves fresh air, if possible keep the window opened a crack
- Have pictures of her family, pets & friends in view
- Play music, she is a classical choral singer and has performed in community musical theatre, loves Bruce Springsteen and Emmylou Harris
- She is a practicing Catholic, if things go south, arrange for a call with Father Ray

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Questions?

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Resources for Older Adults

Maryland Mental Health Association resources for Older Adults/coronavirus https://www.mhamd.org/coronavirus/older-adult-resources/

Better Health While Aging Website, https://betterhealthwhileaging.net/coronavirus-and-older-adults-3-27-2020/

Mutual Aid for Covid-19, connects community volunteers with those who need support, https://www.covaid.co/

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Disability Community Advocates Offer Excellent Resources…

- Brain Injury Association of America https://www.biausa.org/brain-injury/community/covid-19-resources
- National Center on Applied Person-Centered Practices and Systems https://ncapps.acl.gov/covid-19-resources.html
- Helen Sanderson and Associates http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/
- National Disability Rights Network https://www.ndrn.org/issues/covid-19/
- Green Mountain Self Advocates http://www.gmsavt.org/
- Model Systems Knowledge Translation Center TBI Resources to Help Stay Healthy During the Covid-19 Pandemic https://msktc.org/sites/default/files/MSKTC-TBI_COVID-19-Resource-Flyer.pdf

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The Public and Behavioral Health Communities have acted quickly to validate the challenges of this pandemic and offer resources for support-for the general public

- Centers for Disease Control and Prevention:

https://www.cdc.gov/coronavirus/2019-nCoV/index.html

- Johns Hopkins Coronavirus Resource Center:

https://coronavirus.jhu.edu/us-map

- Mayo Clinic:

https://www.mayoclinic.org/diseases-conditions/coronavirus/in-depth/mental-health-covid-19/art-20482731

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Contacts

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