Elder Tree Baseline Survey

University of Wisconsin – Madison; Madison, WI

This is a questionnaire designed to be completed by elderly patients or their caregivers in the patient home. The tool includes questions to assess attitudes of social media and mobile homes.

StudyID: _____

ElderTree
Baseline Survey

Thank you for taking part in this study. Your answers on this survey are important to us. Any information you share is confidential. If you feel uncomfortable with any question, you can skip it. You are free to stop filling out the survey at any time.

INSTRUCTIONS:

Please check one box per question/row unless otherwise indicated. Special instructions will be included in brackets ([ ]) or after an arrow (→) where needed.

1. **What is your gender?**
   - ❑ Male
   - ❑ Female

2. **Which of the following best describe your race and ethnicity?** [CHECK ALL THAT APPLY]
   - ❑ White/Caucasian
   - ❑ Black or African-American
   - ❑ Hispanic or Latino
   - ❑ American Indian or Alaska Native
   - ❑ Asian or Asian-American
   - ❑ Hawaiian Native or Pacific Islander
   - ❑ Other _____

3. **What is the highest grade or level of education you have completed?**
   - ❑ Less than high school
   - ❑ Some high school
   - ❑ High school graduate
   - ❑ Some college or post-high school training
   - ❑ College graduate
   - ❑ Other _____

4. **What is your zip code?** _____

5. Which of the following <u>best</u> describes your living arrangement?

- ❑ Live in your own home or apartment
- ❑ Live in an independent retirement community
- ❑ Live in the home or apartment of your son/daughter, other family, or friends
- ❑ Live in a residential care facility where you have your own stove
- ❑ Live in a nursing home
- ❑ Other _____

6. Does anyone else live with you?

- ❑ No
- ❑ Yes → If so, who lives with you? [CHECK ALL THAT APPLY]
  - ❑ Spouse/partner
  - ❑ Son or daughter
  - ❑ Other family members or friends
  - ❑ Paid caregiver
  - ❑ Other _____

7. Please rate your comfort with each of the following technologies.

	Very uncomfortable	**Somewhat uncomfortable**	**Neither comfortable or uncomfortable**	**Somewhat comfortable**	**Very comfortable**	**Never used**
a. A Smart phone or Tablet	❑	❑	❑	❑	❑	❑
b. Desktop or laptop computer	❑	❑	❑	❑	❑	❑
c. Email	❑	❑	❑	❑	❑	❑
d. Facebook	❑	❑	❑	❑	❑	❑

8. **Do you have physical limitations that make it hard to use any of the technologies listed above? If you manage with a hearing aid or with glasses, that doesn't count.** [CHECK ALL THAT APPLY]
   - ❑ Too hard to hear, even with a hearing aid
   - ❑ Too hard to see, even with glasses
   - ❑ Too hard to use, because of arthritis, hand tremors, etc.
   - ❑ Other: _____
   - ❑ None of the above

DAILY ACTIVITIES

9. **Think about each of the following activities of daily life. How have they been going for you in the last few weeks?**

	Fine, I do it myself	OK, I have the help I need	Challenging, but I can manage	Difficult, I need more help from others
a. Getting to places outside the home (e.g., drive, take the bus)	❑	❑	❑	❑
b. Moving/walking around the home	❑	❑	❑	❑
c. Taking your medications	❑	❑	❑	❑
d. Planning and preparing meals	❑	❑	❑	❑
e. Bathing and using the toilet	❑	❑	❑	❑
f. Dealing with finances	❑	❑	❑	❑

MEDICAL VISITS

10. Please fill in the blank with the approximate number of times each event has happened to you as a patient. If none, write "0".

*In the **past 6 months**, about how many…*	
a. nights did you stay at a full-service hospital?	
b. nights did you spend in an assisted living facility or nursing home?	
c. times did you go to the emergency room?	
d. times did you go to urgent care?	
e. times did you visit your primary care clinic?	
f. other health care visits (i.e. specialty clinic, physical therapy…) Please list type of visit and number of times visited in the past 6 months _____	

QUALITY OF LIFE

11. Please respond to each item by marking one box per row.

	Poor	Fair	Good	Very good	Excellent
a. In general, would you say your health is?	❑	❑	❑	❑	❑
b. In general, would you say your quality of life is?	❑	❑	❑	❑	❑
c. In general, how would you rate your physical health?	❑	❑	❑	❑	❑
d. In general, how would you rate your mental health, including your mood and your ability to think?	❑	❑	❑	❑	❑
e. In general, how would you rate your satisfaction with your social activities and relationships?	❑	❑	❑	❑	❑
f. In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)	❑	❑	❑	❑	❑

	Not at all	A little	Moderately	Mostly	Completely
g. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	❑	❑	❑	❑	❑

In the past 7 days…	Never	Rarely	Sometimes	Often	Always
h. How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	❑	❑	❑	❑	❑

In the past 7 days…	None	Mild	Moderate	Severe	Very severe
i. How would you rate your fatigue on average?	❑	❑	❑	❑	❑

In the past 7 days…	**No pain**										**Worst imaginable pain**
j. How would you rate your pain on average?	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑

SOCIAL NETWORK

People sometimes look to others for support. This may include interactions online using a desktop, laptop, or tablet computer or a smartphone.

12. These items are about support <u>you provide</u> to another person.

How often is there someone…	**Never**	**Seldom**	**Sometimes**	**Often**	**Most of the time**
a. who can count on you to listen when they need to talk?	❑	❑	❑	❑	❑
b. who can get information from you to help them understand a situation?	❑	❑	❑	❑	❑
c. who can share their most private worries and fears with you?	❑	❑	❑	❑	❑
d. who can get suggestions from you about how to deal with a personal problem?	❑	❑	❑	❑	❑
e. who can confide in you or talk to you about themselves or their problems?	❑	❑	❑	❑	❑
f. who knows you understand their problems?	❑	❑	❑	❑	❑
g. who can count on you to give them good advice about a crisis?	❑	❑	❑	❑	❑
h. who really wants your advice?	❑	❑	❑	❑	❑

13. These items are about support <u>you receive</u> from another person.

How often is there someone…	Never	Seldom	Sometimes	Often	Most of the time
a. you can count on to listen to you when you need to talk?	❑	❑	❑	❑	❑
b. who gives you information to help you understand a situation?	❑	❑	❑	❑	❑
c. with whom to share your most private worries and fears?	❑	❑	❑	❑	❑
d. to turn to for suggestions about how to deal with a personal problem?	❑	❑	❑	❑	❑
e. to help you if you were confined to bed?	❑	❑	❑	❑	❑
f. to take you to the doctor if you needed it?	❑	❑	❑	❑	❑
g. to prepare your meals if you were unable to do it yourself?	❑	❑	❑	❑	❑
h. to help with daily chores if you were sick?	❑	❑	❑	❑	❑
i. to love and make you feel wanted?	❑	❑	❑	❑	❑
j. with whom you can have a good time?	❑	❑	❑	❑	❑
k. to confide in or talk to about yourself or your problems	❑	❑	❑	❑	❑
l. who understands your problems	❑	❑	❑	❑	❑
m. to give you good advice about a crisis	❑	❑	❑	❑	❑
n. whose advice you really want	❑	❑	❑	❑	❑

14. About how many people would you say…

a. you can count on to listen to you when <u>you</u> need to talk?	
b. count on you to listen to them when <u>they</u> need to talk?	
c. you can count on for help with daily activities?	
d. show you love and affection?	
e. get together with you to do something enjoyable?	

DRIVING & TRANSPORTATION

15. Please rate how easy you find each of the following.

	Very Difficult	Somewhat Difficult	Neither Difficult nor Easy	Somewhat Easy	Very Easy	Don't do it
a. Coordinating driving/riding to an event with another person	❑	❑	❑	❑	❑	❑
b. Finding a ride to an event	❑	❑	❑	❑	❑	❑
c. Finding the destination when travelling to an unfamiliar place	❑	❑	❑	❑	❑	❑
d. Finding the destination when traveling a long distance	❑	❑	❑	❑	❑	❑

16. Please rate your level of comfort with each of the following.

	Very uncomfortable	Somewhat uncomfortable	Neither comfortable or uncomfortable	Somewhat comfortable	Very comfortable	Don't do it
a. Asking for a ride from another person	❑	❑	❑	❑	❑	❑

17. Over the last 2 weeks, how often did you experience the following situations?

	Never	Several days	About half the days	More than half the days	Nearly every day	Didn't do it
a. Missed an event because you could not find a ride?	❑	❑	❑	❑	❑	❑

18. Do you currently drive?

❑ Yes, I drive

❑ No, I do not drive. → If no, why not? _____

If you do not drive, please skip to the next section of questions on Falls Risk (#22).

19. Please rate your level of comfort with each of the following.

	Very uncomfortable	Somewhat uncomfortable	Neither comfortable or uncomfortable	Somewhat comfortable	Very comfortable	Don't do it
a. Driving	❑	❑	❑	❑	❑	❑
b. Offering a ride to another person	❑	❑	❑	❑	❑	❑

20. Over the last 2 weeks, how often did you experience the following situations?

	Never	Several days	About half the days	More than half the days	Nearly every day	Didn't do it
a. Missed or arrived late to an event because you had difficulty navigating to your destination?	❑	❑	❑	❑	❑	❑

21. Please fill in the blank with the approximate number of times each event has happened to you as a driver. If none, write "0".

*In the **past 6 months**, about how many…*	
a. car crashes have you been in as a driver?	
b. near-miss car crashes have you been in as a driver?	

FALLS RISK

22. A fall is when your body goes to the ground without being pushed. The following two questions are about any falls you may have had in the past 6 months.

*In the **past 6 months** …*	
a. About how many times have you fallen?	
b. How many of these falls require medical attention?	

23. How much does each statement describe the things you do in your daily life?

	Never	Sometimes	Often	Always	Does not apply
a. I talk with others about things I do that might help prevent a fall.	❑	❑	❑	❑	❑
b. I use a firm handhold when I bend over to reach something	❑	❑	❑	❑	❑
c. When I need it, I use a cane or walker.	❑	❑	❑	❑	❑
d. When I am feeling unwell, I take particular care doing everyday things.	❑	❑	❑	❑	❑
e. I hurry when I do things.	❑	❑	❑	❑	
f. I turn around quickly.	❑	❑	❑	❑	
These are things you do indoors	**Never**	**Sometimes**	**Often**	**Always**	**Does not apply**
g. To reach something up high I use the nearest chair, or whatever furniture is handy, to climb on.	❑	❑	❑	❑	❑
h. When I am feeling ill, I take special care of how I get up from a chair and move around.	❑	❑	❑	❑	❑
These are about lighting and eyesight	**Never**	**Sometimes**	**Often**	**Always**	**Does not apply**
i. I get help when I need to change a light bulb.	❑	❑	❑	❑	
j. I use a light if I get up during the night.	❑	❑	❑	❑	
k. I adjust the lighting at home to suit my eyesight.	❑	❑	❑	❑	
These are about things outdoors	**Never**	**Sometimes**	**Often**	**Always**	**Does not apply**
l. When I walk outdoors, I look ahead for potential hazards.	❑	❑	❑	❑	
m. When I go outdoors, I think about how to move around carefully.	❑	❑	❑	❑	
n. I cross at traffic lights or pedestrian crossings whenever possible.	❑	❑	❑	❑	❑
o. I hold onto a handrail when I climb stairs.	❑	❑	❑	❑	❑

MEDICAL CONCERNS

24. To what extent would you estimate that you take your medication doses?

Never	Rarely	Sometimes	Often	Always	Does Not Apply (no medications prescribed)
❑	❑	❑	❑	❑	❑

25. Are you currently taking any of the following types of medicines?

	No, don't take any	Yes, for past 5 months or less	Yes for past 6 months or more
a. Medications to thin your blood, (such as warfarin)	❑	❑	❑
b. Insulin for high blood sugar or diabetes	❑	❑	❑
c. Oral medications for high blood sugar or diabetes	❑	❑	❑

26. Have you experienced any of the following in the past month?

	No	Yes
a. Blood in your urine?	❑	❑
b. Blood in your stool or black tarry stools?	❑	❑
c. A severe nosebleed?	❑	❑
d. Coughed up blood?	❑	❑
e. Significant bruising?	❑	❑
f. Morning headaches?	❑	❑
g. Nightmares?	❑	❑
h. Night sweats?	❑	❑
i. Lightheadedness?	❑	❑
j. Shakiness or weakness?	❑	❑
k. Intense hunger?	❑	❑
l. Times when you passed out, fainted, or lost consciousness, even for a short time?	❑	❑
m. Increased thirst?	❑	❑
n. Dry mouth?	❑	❑
o. Decreased appetite?	❑	❑
p. Nausea or vomiting?	❑	❑
q. Abdominal pain?	❑	❑
r. Frequent urination at night? (Do you have to get up to urinate 3 or more times a night?)	❑	❑

EMOTIONAL STATUS

27. Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
a. Little interest or pleasure in doing things	❑	❑	❑	❑
b. Feeling down, depressed, or hopeless	❑	❑	❑	❑
c. Trouble falling or staying asleep, or sleeping too much	❑	❑	❑	❑
d. Feeling tired or having little energy	❑	❑	❑	❑
e. Poor appetite or overeating	❑	❑	❑	❑
f. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	❑	❑	❑	❑
g. Trouble concentrating on things, such as reading the newspaper or watching television	❑	❑	❑	❑
h. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	❑	❑	❑	❑

27a. Please tell us how often each of the statements below is descriptive of you.

How often do you feel…	Never	Rarely	Sometimes	Always
1. that you are "in tune" with the people around you?	❑	❑	❑	❑
2. that you lack companionship?	❑	❑	❑	❑
3. that there is no one you can turn to?	❑	❑	❑	❑
4. alone?	❑	❑	❑	❑
5. part of a group of friends?	❑	❑	❑	❑
6. that you have a lot in common with the people around you?	❑	❑	❑	❑
7. that you are no longer close to anyone?	❑	❑	❑	❑
8. that your interests and ideas are not shared by those around you?	❑	❑	❑	❑
9. outgoing and friendly?	❑	❑	❑	❑
10. close to people?	❑	❑	❑	❑
11. left out?	❑	❑	❑	❑
12. that your relationships with others are not meaningful?	❑	❑	❑	❑
13. that no one really knows you well?	❑	❑	❑	❑
14. isolated from others?	❑	❑	❑	❑
15. you can find companionship when you want it?	❑	❑	❑	❑
16. that there are people who really understand you?	❑	❑	❑	❑
17. do you feel shy?	❑	❑	❑	❑
18. that people are around you but not with you?	❑	❑	❑	❑
19. that there are people you can talk to?	❑	❑	❑	❑
20. that there are people you can turn to?	❑	❑	❑	❑

HOME SERVICES

28. Overall tell us how satisfied you are with professional/paid services delivered to your home for you or an older adult you care for?

	Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied	Not applicable
a. Showering or bathing or grooming	❑	❑	❑	❑	❑	❑
b. In home meal preparation or meals-on-wheels	❑	❑	❑	❑	❑	❑
c. Toileting and incontinence care	❑	❑	❑	❑	❑	❑
d. Medical support services*	❑	❑	❑	❑	❑	❑

* reminders to take medications, taking blood pressure, monitor weight for gain or loss, observe for injuries (bruises, limping) monitor for pain

OTHER SUPPORT

29.In the past 6 months, have you participated in any of the following activities, either in person, online or via the telephone? [CHECK ALL THAT APPLY FOR EACH ROW]

	No	Yes, In person	Yes, By Internet	Yes, Telephone
a. Individual or family counseling/psychotherapy	❑	❑	❑	❑
b. Health or medical-related support group	❑	❑	❑	❑
c. Caregiving support group	❑	❑	❑	❑
d. Social club/group (i.e., book club, recreation, sports league)	❑	❑	❑	❑
e. Faith-based group	❑	❑	❑	❑
f. Other, please describe:	❑	❑	❑	❑
g. Other, please describe: _____	❑	❑	❑	❑

The remaining survey questions are about your experience providing supportive care for an older adult.

> For this study, we define "supportive care" as providing regular, ongoing assistance to a spouse, family member, or friend, without pay, with the intent of helping that person keep their independence.
>
> Going along to doctor appointments, talking to doctors/nurses, managing medications, bathing and dressing, cleaning, preparing meals, paying bills, or providing transportation to social activities are all types of assistance that might be included in supportive care.
>
> The person you are providing supportive care for may live with you or separate from you.

30. Are you <u>currently</u> providing supportive care for an <u>older adult</u>? [Please follow the instructions after the arrow for the box you check.]

- ❑ **No** → please skip the remaining questions and mail in the survey.
- ❑ **Yes** → please answer the remaining questions on Caring for an Older Adult before mailing in the survey.

<u>CARING FOR AN OLDER ADULT</u>

31. Think about the older adult you are providing supportive care for. How has it been going for you in the last few weeks helping this person…

	Don't have to do it	OK, It's under control	Challenging, but I can manage	Difficult, I need more help from others
a. Getting to places outside the home (e.g., drive, take the bus)	❑	❑	❑	❑
b. Moving/Walking around the home	❑	❑	❑	❑
c. Taking their medications	❑	❑	❑	❑
d. Planning and prepare meals	❑	❑	❑	❑
e. Bathing and using the toilet	❑	❑	❑	❑
f. Dealing with finances	❑	❑	❑	❑

32. Now we're going to talk about some feelings you may be having about providing supportive care <u>for an older adult</u>. For each statement, please tell us how much you agree or disagree with the statement.

	Disagree a lot	Disagree a little	Neither Agree nor Disagree	Agree a little	Agree a lot
a. No matter how much I do, somehow I feel guilty about not doing enough for this person.	❑	❑	❑	❑	❑
b. I can fit in most of the things I need to do in spite of the time taken by caring for this person.	❑	❑	❑	❑	❑
c. Taking care of this person gives me a trapped feeling.	❑	❑	❑	❑	❑
d. I get a sense of satisfaction from helping this person.	❑	❑	❑	❑	❑

33. Please tell us how often you feel this way:

How often do you feel...	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
a. that helping this person has made you feel closer to her/him?	❑	❑	❑	❑	❑
b. uncertain about what to do about this person?	❑	❑	❑	❑	❑
c. that you should be doing more for this person?	❑	❑	❑	❑	❑
d. that you could do a better job in caring for this person?	❑	❑	❑	❑	❑

How often do you feel...	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
e. that you really enjoy being with this person?	❑	❑	❑	❑	❑
f. that taking responsibility for this person gives your self-esteem a boost?	❑	❑	❑	❑	❑
g. that this person's pleasure over some little thing gives you pleasure?	❑	❑	❑	❑	❑
h. that your health has suffered because of the care you must give this person?	❑	❑	❑	❑	❑
i. that because of the time you spend with this person you don't have enough time for yourself?	❑	❑	❑	❑	❑
j. that your social life has suffered because you are caring for this person?	❑	❑	❑	❑	❑
k. very tired as a result of caring for this person?	❑	❑	❑	❑	❑
l. that caring for this person gives more meaning to your life?	❑	❑	❑	❑	❑
m. that you will be unable to care for this person much longer?	❑	❑	❑	❑	❑
n. isolated and alone as a result of caring for this person?	❑	❑	❑	❑	❑
o. that you have lost control of your life because of caring for this person?	❑	❑	❑	❑	❑

34. How often <u>in the last 4 weeks</u> have you used each of the following strategies to deal with the stress of providing care <u>to the older adult</u>?

	Never	Rarely/ seldom	Sometimes	Often	Most of the time
a. Made the most of it.	❑	❑	❑	❑	❑
b. Wished you could change the way you felt.	❑	❑	❑	❑	❑
c. Did something totally new to solve the problem.	❑	❑	❑	❑	❑
d. Wished you could change what had happened.	❑	❑	❑	❑	❑
e. You knew what had to be done, so you tried harder to make things work.	❑	❑	❑	❑	❑
f. Accepted the situation.	❑	❑	❑	❑	❑
g. Daydreamed or imagined a better time or place then the one you were in.	❑	❑	❑	❑	❑
h. Felt inspired to be creative in solving the problem.	❑	❑	❑	❑	❑
i. Refused to let it get to you.	❑	❑	❑	❑	❑
j. Hoped a miracle would happen.	❑	❑	❑	❑	❑
k. Came up with a couple of different solutions to the problem.	❑	❑	❑	❑	❑
l. Wished you were a stronger person to deal with it better.	❑	❑	❑	❑	❑
m. Made a plan of action and followed it.	❑	❑	❑	❑	❑
n. Told yourself things to help you feel better.	❑	❑	❑	❑	❑
o. Changed something about yourself so you could deal with the situation better.	❑	❑	❑	❑	❑
p. Had fantasies about how things might turn out.	❑	❑	❑	❑	❑