

An Examination of Sensory Contributions to
Independent Activities of Daily Living

Dan Roberts

An Examination of Sensory Contributions to Independent Daily Living Activities

Introduction & Background

The English Longitudinal Study of Ageing¹ has found that people with poor eyesight are three to five times more likely than those with good eyesight to suffer from low quality of life, poor psychological health, and depression. When those inequalities are accounted for, however, the impact of poor eyesight itself makes almost no difference. Low vision rehabilitation can help balance many inequalities by strengthening other senses that have lain dormant in deference to sight. By awakening those senses, most independent activities of daily living (ADLs) can be continued, and quality of life (QOL) can be maintained.

Chronic adult onset retinal diseases present a unique challenge, in that the course of such diseases is usually slow and progressive. A newly-diagnosed person is commonly not yet motivated to seek or commit to low vision rehabilitation, and the time for rehabilitation differs with everyone, depending upon level of visual function. When loss of function, therefore, eventually does generate a need for intervention, the person may be at a loss as to how to proceed. This can cause confusion, depression, and noncompliance, lessening the chances for a satisfactory QOL.

To test the validity of this observation, a questionnaire was submitted to a random sample of 50 people affected by various stages of age-related macular degeneration (AMD). The specific purposes of the questionnaire were:

¹ Marmot M, Banks J, Blundell R, Lessof C, Nazroo J. Health, Wealth and Lifestyles of the Older Population in England. The 2002 English Longitudinal Study of Ageing. London: Institute for Fiscal Studies, 2003.

- To determine what percentage of people in the Internet macular degeneration community have not received low vision rehabilitation (LVR).
- To target specific reasons why some people with AMD do not take advantage of LVR.

Following a brief description of LVR, participants were asked to respond "yes" or "no" to the question, "Have you gone through professional low vision rehabilitation intervention?" Those who responded "no" were asked to select from three explanations:

1. I didn't know it was available.
2. I knew it was available but was not encouraged to pursue it.
3. I was encouraged to pursue it, but chose not to participate.

Those who selected #3 were asked to select from an additional three explanations:

1. I didn't feel it was necessary.
2. I couldn't afford it.
3. It was too inconvenient, due to distance or time.

Of the 50 respondents, 46 (92%) reported not having undergone low vision rehabilitation for the following reasons:

- 1 (0.02) did not know LVR was available.
- 37 (0.80) knew LVR was available, but were not encouraged to pursue it.
- 4 (0.09) were encouraged to pursue LVR, but considered it unnecessary, either because of still-satisfactory vision or knowledge acquired on their own.
- 4 (0.09) were encouraged to pursue LVR, but couldn't afford it.
- 29 (%) said LVR sessions would be inconvenient, due to distance or time.

This informal survey reveals several problems, the two most obvious being:

1. A significant majority of the professional sector either misunderstands or is ignoring the importance of low vision rehabilitation in the continuum of care.
2. Low vision rehabilitation needs to be made more readily available to patients on an as-needed basis.

All patients and their families need to be educated about the benefits and availability of LVR, and then reminded periodically as the disease progresses. This includes people who would benefit from immediate intervention and those who could be spared anxiety and depression by knowing that professional and effective intervention is available when and if they need it.

Purpose of this project

It was determined that a newly diagnosed person might benefit from having an overview of all independent ADLs that are important to his or her needs and goals, with identification of nonvisual senses that can take over in each instance as needed and desired. Specific low vision interventions would include:

- direction to information about assistive devices and technology
- introduction to practical living skills
- introduction to additional resources for accomplishing each independent ADL

This “self-help guide” would also:

- help smooth the transition from visual to nonvisual practices by raising awareness of the role other senses can play in accomplishment of independent ADLs.
- create a realization that , even though sight may be the most convenient and aesthetically favored of the five senses, it is not necessarily the .

Procedure

The first step in creating the guide was to identify the level of contributions to all independent ADLs by each of the five physiological senses: sight, touch, hearing, smell, and taste. The senses were then identified as primary contributors, alternate contributors, or non-contributors to each independent ADL. The next step was to connect each alternate contributor with information about interventions that would facilitate its use. Finally, the entire document was printed in large font and written in language tailored for optical character recognition devices and computer screen readers. The guide is also available in audio format.

Twenty-one categories of independent ADLs were identified as important to the QOL of senior adults. A total of 81 independent ADLs specific to those categories were also identified. The list was based upon the standard activities of daily living established and revised by several researchers over the past half-century, beginning with Katz et al. (1963; Katz, 1983) and Fillenbaum et al. (1978). It was then expanded to include activities deemed important to senior adults with sight loss from age-related macular degeneration and related diseases. This additional information was drawn from hundreds of interviews with low vision seniors and caregivers via live support groups, Internet discussion groups, and personal conversations. To distinguish assisted activities from unassisted activities, the more commonly used phrases, “activities of daily living” and “independent living skills”, were combined as “independent activities of daily living” (independent ADLs). They are:

1. Managing health and personal hygiene
2. Dressing
3. Eating
4. Moving about the home (functional mobility)

5. Toileting
6. Managing Personal Finances
7. Practical writing
8. Cleaning the house
9. Taking medications
10. Shopping
11. Operating the telephone
12. Reading
13. Participating in games and hobbies
14. Experiencing/participating in live or electronic entertainment
15. Socializing & communicating with others
16. Traveling away from home
17. Responding to emergencies
18. Preparing meals
19. Following safety procedures
20. Doing laundry
21. Maintaining and caring for home and property

Each independent ADL was analyzed to identify which of the five physiological senses are primary contributors to it in people with healthy vision. Each of the remaining senses were identified as either potentially helpful “alternate contributors” or ineffective “non-contributors”. Each alternate contributor was connected to one or more of the eight “assistive procedures” commonly introduced in low vision rehabilitation:

1. Labeling

2. Modifying or developing techniques
3. Using Braille
4. Using high technology devices or software
5. Modifying objects or environment
6. Using orientation and mobility skills
7. Utilizing a public service
8. Using low vision materials and non-optical devices or equipment

To organize the data, a “Table of Sensory Contributors” was created, from which computations were made and observations and conclusions were drawn. The table is presented here, followed by a summary, conclusions, and recommendations for practical application.

Table of Sensory Contributors

Footnote numbers refer to these assistive procedures:

1. Labeling
2. Modifying or developing techniques
3. Using Braille
4. Using high technology devices or software
5. Modifying objects or environment
6. Using orientation and mobility skills
7. Utilizing a public service
8. Using low vision materials and non-optical devices or equipment

Contributors & Assistive Procedures

(✓=primary A=alternative ●=non-contributor)

<u>Independent Activities of Daily Living (ADLs)</u>	<u>sight</u>	<u>touch</u>	<u>hearing</u>	<u>smell</u>	<u>taste</u>
1. Managing health and personal hygiene					
a. Using toothpaste	✓	A ¹	●	A ²	A ²
b. Filling the tub and sink	✓	A ²	●	●	●
c. Washing skin and hair	✓	A	●	A ²	●
d. Identifying/applying deodorant	✓	A ¹	●	A ²	●
e. Brushing/combing/styling hair	✓	A	●	●	●
f. Trimming/shaving facial and body hair	✓	A	●	●	●
g. Identify/applying lotions, creams, and scents	✓	A ^{1, 2}	●	A ²	●
h. Identifying/applying makeup	✓	A ^{1, 2}	●	A ²	●
i. Manicuring/pedicuring	✓	A ²	●	A ²	●
j. Cleaning ears and nostrils	✓	A ²	●	●	●
k. Checking vital signs, such as blood pressure, glucose level, temperature, and weight	✓	●	A ²	●	●
2. Dressing					
a. Identifying/donning/storing clothing, accessories, and footwear	✓	A ^{1, 2, 3, 5}	A ⁴	●	●
3. Eating					
a. Locating/using dishes, utensils, and glassware	✓	A ^{2, 5}	●	●	●
b. Cutting food	✓	A ^{2, 5}	●	●	●
c. Applying condiments	✓	A ^{1, 2, 5}	●	A ²	A ²

Contributors & Assistive Procedures

(✓=primary A=alternative ●=non-contributor)

Independent Activities of Daily Living (ADLs) **sight touch hearing smell taste**

4. Moving about the home (functional mobility)

a. Locating/identifying furniture and appliances	✓	A ^{2, 5, 6}	●	●	●
b. Negotiating steps	✓	A ^{2, 5, 6}	●	●	●
c. Passing through entryways	✓	A ^{2, 5, 6}	●	●	●
d. Closing/securing doors and windows	✓	A ^{2, 5}	●	●	●
e. Opening/shutting cabinets and drawers	✓	A ^{2, 5}	●	●	●

5. Toileting

a. Operating the toilet	✓	A ^{2, 5}	A ²	●	●
b. Personal cleansing	✓	A ²	●	●	●

6. Managing Personal Finances

a. Paying bills	✓	A ^{2, 3, 5, 7, 8}	A ⁴	●	●
b. Making deposits and withdrawals	✓	A ^{2, 7, 8}	A ⁴	●	●

7. Practical writing

a. Reminders, lists, labels, etc.)	✓	A ^{3, 8}	A ⁴	●	●
------------------------------------	---	-------------------	----------------	---	---

8. Cleaning the house

a. Cleaning floors	✓	A ^{2, 5}	A ²	●	●
b. Washing windows, mirrors, and walls	✓	A ^{2, 5}	●	●	●
c. Cleaning/dusting furniture, shelves, and appliances	✓	A ^{2, 5}	●	●	●
d. Organizing clutter	✓	A ^{2, 5}	●	●	●
e. Arranging decorative items (knick-knacks, pictures, etc.)	✓	A ^{2, 5}	●	●	●
f. Making beds	✓	A ^{2, 5}	●	●	●

9. Taking medications

a. Identifying/organizing medicines	✓	A ^{1, 3, 5}	A ⁴	A ²	●
-------------------------------------	---	----------------------	----------------	----------------	---

10. Shopping

a. Locating/identifying products	✓	A ²	A ⁴	A ²	●
b. Identifying prices	✓	●	A ⁴	●	●
c. Identifying currency	✓	A ²	A ⁴	●	●
d. Identifying colors (eg. apparel)	✓	●	A ⁴	●	●

Contributors & Assistive Procedures

(✓=primary A=alternative ●=non-contributor)

Independent Activities of Daily Living (ADLs) sight touch hearing smell taste

11. Operating the telephone

- | | | | | | |
|-------------------------------------|---|----------------------|-------------------|---|---|
| a. Direct dialing | ✓ | A ^{1, 2, 5} | A ^{4, 7} | ● | ● |
| b. Finding, recalling phone numbers | ✓ | A ^{3, 5} | A ^{4, 7} | ● | ● |

12. Reading

- | | | | | | |
|---|---|-------------------|-------------------|---|---|
| a. Leisure reading (books, magazines, music) | ✓ | A ³ | A ^{4, 7} | ● | ● |
| b. Practical reading (instructions, appliance controls, labels, calendars, schedules, etc.) | ✓ | A ³ | A ⁴ | ● | ● |
| c. Telling time and temperature | ✓ | A ^{3, 4} | A ⁸ | ● | ● |

13. Participating in games and hobbies

- | | | | | | |
|--|---|----------------------|----------------|---|---|
| a. Playing electronic and table games | ✓ | A ^{3, 5} | ● | ● | ● |
| b. Working word puzzles | ✓ | A ³ | A ⁴ | ● | ● |
| c. Needlework | ✓ | A ^{1, 2, 5} | ● | ● | ● |
| d. Crafting/woodworking | ✓ | A ^{1, 2, 5} | ● | ● | ● |
| e. Participating in individual and team sports | ✓ | A ^{2, 5, 8} | A ² | ● | ● |
| f. Caring for/repairing machinery | ✓ | A ^{2, 5} | A ² | ● | ● |
| g. Sculpting, painting, drawing, photographing | ✓ | A ^{2, 4} | A ⁴ | ● | ● |

14. Experiencing/participating in live or electronic entertainment

- | | | | | | |
|---|---|-------------------|----------------|---|---|
| a. Playing an instrument alone or with others | A | ✓ | A | ● | ● |
| b. Using the television, radio, or computer | ✓ | A ^{2, 3} | A ⁴ | ● | ● |
| c. Attending a live event | ✓ | ● | A ⁷ | ● | ● |
| d. Dancing | ● | A ² | ✓ | ● | ● |
| e. Singing | ● | ● | ✓ | ● | ● |

15. Socializing & communicating with others

- | | | | | | |
|---|----------------|-------------------|----------------|----------------|---|
| a. Recognizing others | ✓ | A ² | A ² | A ² | ● |
| b. Conversing in person | A ² | A ² | ✓ | ● | ● |
| c. Participating in electronic social media | ✓ | A ^{2, 4} | A ⁴ | ● | ● |

16. Traveling away from home

- | | | | | | |
|------------------------|---|-------------------------|-------------------------|---|---|
| a. Passengering | ✓ | A ^{3, 7} | A ⁴ | ● | ● |
| b. Operating a vehicle | ✓ | ● | ● | ● | ● |
| c. Walking/hiking | ✓ | A ^{2, 3, 5, 6} | A ^{2, 4, 5, 7} | ● | ● |

17. Responding to emergencies

- | | | | | | |
|--|---|----------------|----------------|---|---|
| a. Locating emergency exits | ✓ | A ⁵ | A ² | ● | ● |
| b. Getting help (Medic Alert, 911, etc.) | ✓ | A ⁴ | A ⁴ | ● | ● |

Contributors & Assistive Procedures

(✓=primary A=alternative ●=non-contributor)

Independent Activities of Daily Living (ADLs)	sight	touch	hearing	smell	taste
a. Locating/using first aid supplies	✓	A ^{1, 3}	●	●	●
b. Identifying danger	A	A ^{2, 6}	✓	A ²	A ²
c. Locating gas, electricity, and water shutoffs	✓	A ^{1, 3}	●	●	●
18. Preparing meals					
a. Locating /identifying/using food products	✓	A ^{1, 2, 3, 5}	A ⁴	A ²	A ²
b. Locating/identifying/using utensils and cookware	✓	A ^{1, 2, 5}	A ²	●	●
c. Using kitchen appliances	✓	A ^{1, 2, 5}	A ²	●	●
d. Measuring and pouring	✓	A ^{2, 8}	●	●	●
e. Setting the table	✓	A ^{2, 5, 8}	●	●	●
f. Cleaning up	✓	A ^{1, 2, 5}	●	●	●
19. Following safety procedures					
a. Plugging and unplugging electrical cords	✓	A ^{1, 2, 5}	●	●	●
b. Operating controls (thermostats, appliances, heaters, etc.)	✓	A ^{1, 3, 5, 8}	●	●	●
c. Using tools	✓	A ^{1, 2, 5}	●	●	●
20. Doing laundry					
a. Separating/sorting clothing	✓	A ^{1, 2, 5}	A ⁴	●	●
b. Operating the washer and dryer	✓	A ¹	A ²	●	●
c. Locating/identifying/measuring soaps and chemicals	✓	A ^{1, 2, 3, 5}	●	A ²	●
21. Maintaining and caring for home and property					
a. Locating/identifying/organizing tools and equipment	✓	A ^{1, 2, 3, 5}	●	●	●
b. Locating/identifying/organizing/measuring lawn and garden chemicals	✓	A ^{1, 2, 3}	●	A ²	●
c. Making minor repairs	✓	A ²	A ²	●	●
d. Mowing/trimming/weeding	✓	A ²	●	●	●
e. Painting/refinishing	✓	A ²	●	●	●
f. Sweeping/raking	✓	A ²	●	●	●
g. Watering	✓	A ²	●	●	●

Tallies:

Number of primary contributors (✓)	76	1	4	0	0
Number of alternate contributors (A)	<u>3</u>	<u>74</u>	<u>36</u>	<u>14</u>	<u>4</u>
Total primary and alternate contributors	79	75	40	14	4
Number of non-contributions (●)	2	6	41	67	77

Summary of the Table of Sensory Contributors

1. An adult with normal physical, sensory, and mental capacities can function in all 81 independent ADLs. Sight is the primary contributor to 76 (0.94) of the independent ADLs. Hearing is the primary contributor to 4 (0.05), and touch is the primary contributor to 1 (0.01). Neither smell nor taste are primary contributors to any ADLs.

With maximum intervention of appropriate instruction, practice, and technology:

- Contributions by touch to the independent ADLs can increase from 1 (0.01) to 75 (0.94), which nearly equals primary sight contributions.
- Contributions by hearing to the independent ADLs can increase from 4 (0.05) to 40 (0.49).
- Contributions by smell to the independent ADLs can increase from 0 (0.00) to 14 (0.18).
- Contributions by taste to the independent ADLs can increase from 0 to 4 (0.05).

2. Total loss of functional sight (81 primary contributors minus 76 primary sight contributors) can result in a drop to 0.06 of independent ADL capacity. Sight is clearly the most numerous primary contributor to independent ADLs, but it can be replaced by all but one alternative contributor, leaving 80 (0.99) independent ADLs intact. The independent ADL currently without an alternate sight contributor is

“operating a vehicle independently,” and that will likely change as new technology evolves.

3. Five(0.06) independent ADLS are primarily nonvisual, needing no intervention in case of sight loss. They are:

- Playing an instrument alone or with others
- Identifying danger
- Dancing
- Singing
- Conversing in person

4. Eight alternative methods are used in a total of 212 instances to replace or supplement sight. From most to least utilized, they are:

- Modifying or developing techniques (84=0.40)
- Modifying objects or environment (39=0.18)
- Using high technology devices or software (26=0.12)
- Labeling (24=0.11)
- Using Braille (18=0.09)
- Using low vision materials and non-optical devices or equipment (8=0.04)
- Utilizing a public service (8=0.04)
- Using orientation and mobility skills (5=0.02)

Conclusions

1. A motivated patient participating in a good low vision rehabilitation program can conceivably preserve or restore 99% of all independent ADLs lost to poor vision. Driving a vehicle independently is the only activity that cannot be replaced at this time, but new technology makes it a future possibility.

2. Timing and degree of loss of contributors to independent ADLs will differ with

each individual. Well-timed introduction of alternate contributors as needed can ease the transition from visual to nonvisual activities. For example:

- a. Introduce a writing template when independent ADL #7b (writing checks) is affected.
- b. Introduce mobility skills when independent ADL #16c (walking/hiking) is affected.

3. Other factors besides loss of sensory contributors may intervene in the successful maintenance of QOL, to include financial status, social support, mental state, and general health. These conditions should also be addressed as part of a low vision rehabilitation program.

4. Taste is observably nonessential, useful mainly for its aesthetic value.

Looking at the evidence, sight might also be considered as nonessential. QOL, however, can be seriously diminished in a person who has become overly dependent upon it, especially if alternatives are not introduced to compensate for the loss.

The culmination of this project is a guide for use by patients or caregivers who find it helpful. It is as current as possible, but it is open to change as procedures and technologies advance. The first version contains:

- A self-evaluation checklist of independent ADLs
- Identification of alternate contributors for each independent ADL
- Lessons about assistive procedures and how to incorporate them into the independent ADLs as needed
- Directories to state rehabilitation agencies, distributors of low vision devices, and distributors of audio books
- Educational material about low vision rehabilitation

“A Self-Help Guide to Nonvisual Skills” is available in printable PDF format from www.mdsupport.org/guide.pdf or in web format at www.mdsupport.org/guide.html

Comments are welcome, and may be sent to director@mdsupport.org