

***THANK YOU FAMILY CAREGIVER ALLIANCE
FOR INVITING US & FOR ALL YOU DO!***

Caregiver Support & The Power of Community

*A Discussion About Schurig Center Services &
the Needs of Brain Injury Survivors
and Caregivers*

WEBINAR PRESENTERS



***Jim Wilson,
Ph.D***

***Clinical
Psychologist***

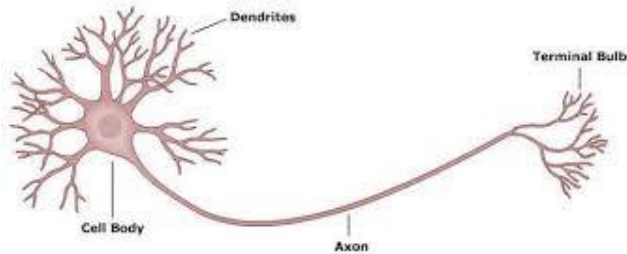
***Patricia Gill,
M.S.***

***Executive
Director***



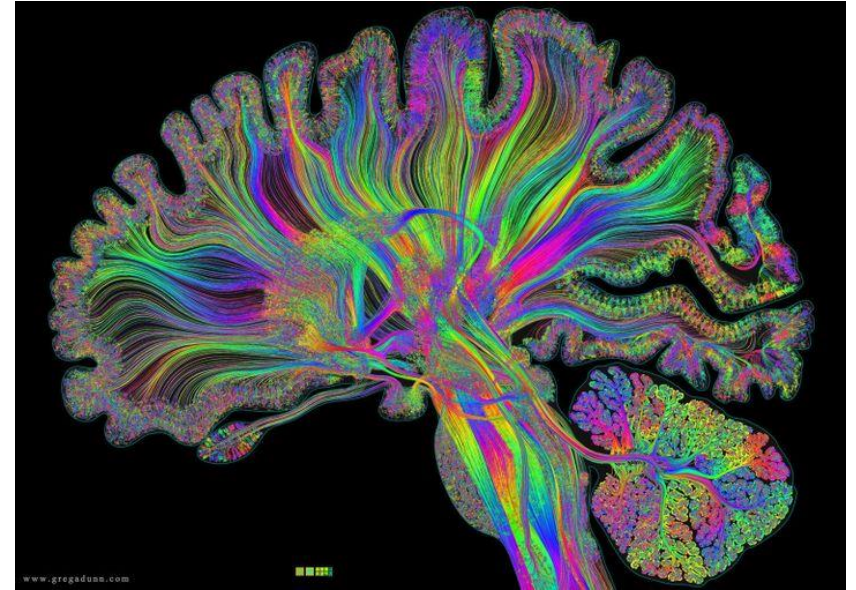
Our Amazing Brain...

The most complex organ of the human body. And the most vulnerable to injury!



20 Billion
Axons

100 Billion Neurons



Each neuron has 7,000 synaptic connections to other neurons

- $7000 \times 100 \text{ Billion} = 700000000000000$
- Total Connections. 7×10^{14}

A computer image of “Self Reflected,” an etching of a human brain created by artists Greg Dunn and Brian Edwards.

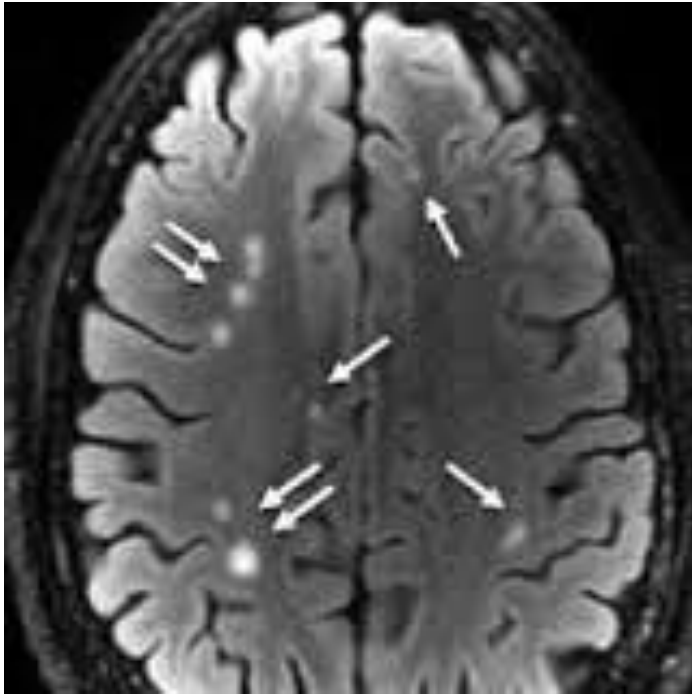
ACQUIRED BRAIN INJURY (ABI)

Caused by events after birth

ABI can result in cognitive, physical, emotional, psychological or behavioral impairments that lead to permanent or temporary changes in functioning.

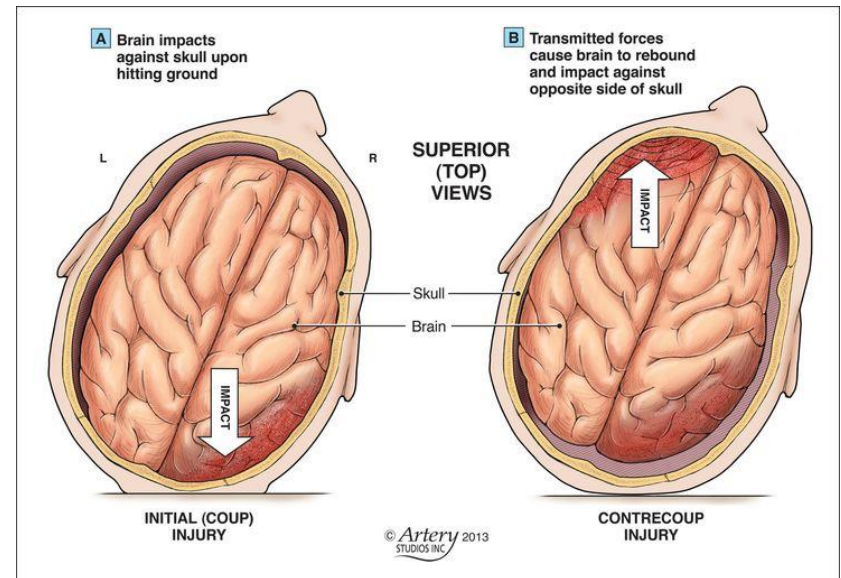
- Traumatic Brain Injury (TBI, mTBI/Concussion)
- Chronic Traumatic Encephalopathy (CTE) (sports-football)
- Hypoxic/Anoxic Brain Injury (heart attack)
- Metabolic Brain Injury (diabetic coma)
- Ischemic Brain Injury (stroke), embolic & hemorrhagic, and rupture (aneurysm)
- Toxic Brain Injury (chemical)(substance abuse)
- Infectious Brain Injury (meningitis, herpes encephalopathy)
- Neoplastic Brain Injury (tumors)

Ontario Brain Injury Association. ["What is Acquired Brain Injury"](#)



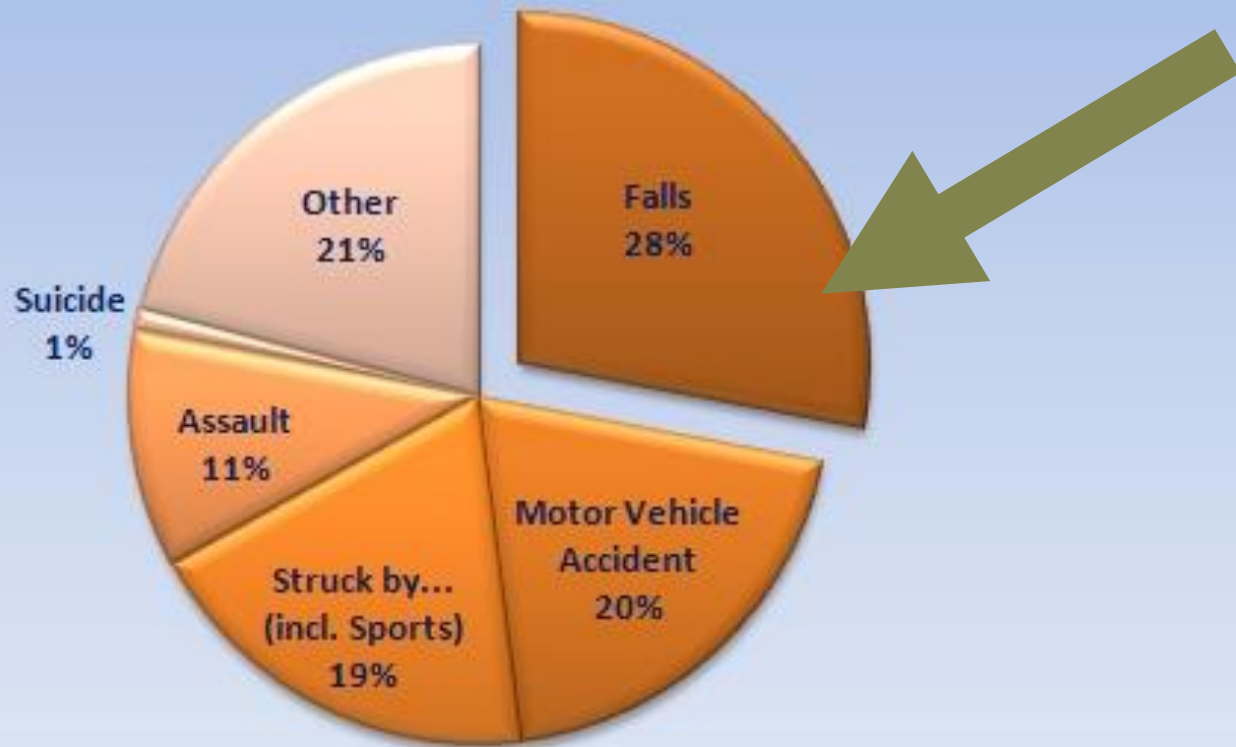
Diffuse Axonal Injury

Coup - Contrecoup Injury



Traumatic Injuries

Major Causes of Traumatic Brain Injuries

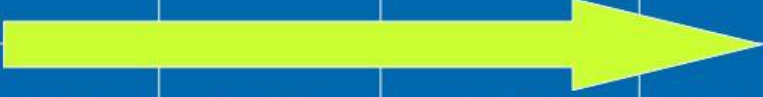


Source: National Center for Injury Prevention and Control, CDC

mTBI/Concussion, PTSD, & Depression

Hoge NEJM Jan. 2008 study (cont.)

	No Injury	Other Injury	mTBI w/ AOC	mTBI w/ LOC
PTSD	9.1%	16.2%	27.3%	43.9%
Depression	3.3%	6.6%	8.4%	22.9%



- mTBI was strongly associated with PTSD and with Depression, so . . .
- Does mTBI cause PTSD & Depression or increase the risk of developing them?

Brain Injuries do not discriminate...

- **Traumatic Brain Injury (TBI):**
 - “Silent Epidemic”
 - 1 every 15 seconds (BIRI, 2014)
 - Leading cause of death <45 yo (Upenn, 2014)
 - > than breast cancer, AIDS, M.S. and spinal cord injury **COMBINED** (Upenn, 2014)
- **Veterans:**
 - >287,000 with TBI since 2000 (U.S. DOD)
 - 83% are mTBI's (U.S. DOD)
 - 54% have co-morbid psychiatric and pain dx (Taylor, 2012)
- **Stroke:**
 - 1 every 40 seconds (Kochanek, 2011)
 - 1 person dies every 4 minutes (CDC 2010)
 - Leading cause of long-term disability (AMA 2014)
 - Est \$36.5 billion per year (AMA 2014)

Necessity is the Mother of Invention

- *Plato*





SCHURIG
CENTER

For Brain Injury Recovery

*“ We help people accept that
their life has changed and to
rethink their dreams. ”*

Karen Schurig

Mother & Founder







Changing Lives for 37 Years

Our mission: To improve the quality of life for survivors of brain injury and their families and to raise awareness about the causes and effects of these disabilities.

*Brain Injury is a pause button.
Schurig Center helps survivors hit play again.*

We Help “Us” – Our Neighbors, Family Members, Friends, Colleagues...We All Know Someone Who's Life Has Been Touched by Injury



- **Julie**, who needed help finding resources to help her husband
- **Bill**, a veteran who lives with side effects of traumatic brain injury
- **Barbara**, whose daughter suffered a brain injury in her 30's from a virus
- **Nancy**, a mother who needs help remembering how to write and receive email messages after a stroke.
- **Joe**, who is rehabilitating to return to work after a concussion from a bicycle accident.



How Schurig Center Helps...

- Tailored services for acquired brain injury survivors (injuries after birth from stroke, traumatic brain injury, concussion, anoxia, viral infections, tumor)
- Design programs that provide an array of 'whole-person' brain injury specific services (support, education, rehabilitative)
- Fill gaps in care + assist with finding community resources
- Reduce isolation and feeling 'alone'
- Make treatment affordable – turn nobody away
 - Sliding-scale/free services, Scholarship Funding
- Collaborate with other healthcare professionals & agencies
- Support Caregivers as well as Survivors
- Improve physical and mental health
 - Decrease re-hospitalization (due to re-injury, mental health)
 - Reduce depression and anxiety (self report, CG report, physician report)
 - Support survivor AND their families

Services Designed to Help These Effects of Brain Injury...

- Behavioral issues
- Language and communication deficits
- Cognitive deficits (memory, problem solving, focus/attention)
- Psychiatric/Psychosocial sequelae (mood, anxiety, depression, irritability)
- Isolation, loneliness, loss of community
- Frustration, boredom, functional decline
- Relationship issues, role changes
- Feeling that “Nobody gets me”
- Of note: Psychosocial challenges are associated with increased mortality and decreased functional outcomes (Winstein et al., 2016)

“Brain Injury is a chronic condition and rehabilitation requires a sustained and coordinated effort from a large team of professionals and paraprofessionals long after the end of formal rehabilitation”

(Guidelines for Adult Stroke Rehabilitation and Recovery. Winstein et al., 2016).

Whole-Person Approach: Therapeutic, Educational, Psychosocial Support

- CORE Therapeutic Program (array of daily classes)
- Computerized Cognitive Training Class (Neuropsychonline)
- Speech Therapy/Aphasia Classes
- CogSmart (UCSD Program – life skills)
- Support Groups for Survivors & Caregivers
- Community Resource Assistance
- Art Therapy Classes
- Concussion Classes & Community Program

Brain Injury Information Handbook

Brain Injury Information Handbook

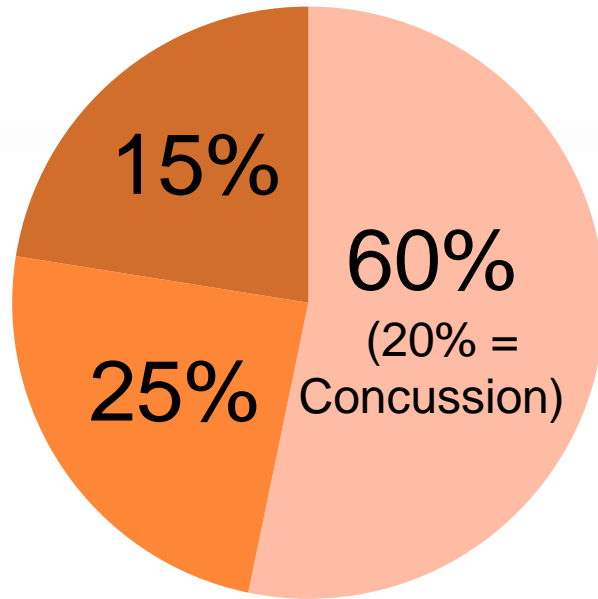


*A Guide for Patients
and Families From
Hospital to Home*

Information and Resource Handbook created to provide guidance and address the commonly asked questions from survivors and families as they navigate the path of rehabilitation from hospital to home.

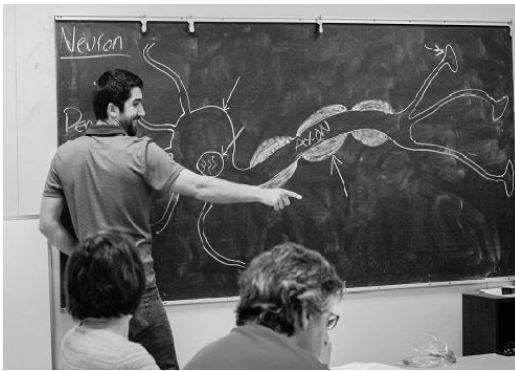
California Pacific Regional Rehabilitation Center
Brain Injury Network of the Bay Area

Who We Serve



- TBI
- Stroke
- Other - anoxia, virus, tumor, AVM

- 500+ Individuals, Caregivers, Professionals
- 4,000+ online info/resources, concussion website (concussionsmartmarin.org)
- Seniors = 34%
- Low Income = 77%



How We Know Our Services Are Helping

- Outcome measures tailored to each service
- Individualized Treatment Plans
- Objective Functional Measures
 - Neuropsychonline assessment, Behavioral Rating Inventory of Executive Function (BRIEF-A), Goal tracking, Speech Therapy
- Surveys – survivors and caregivers
- Annual Results:
 - High satisfaction ratings (90%-100%)
 - Positive improvement rates/goal achievement in all services (in areas of behavior, communication, cognitive ability, quality of life)

Continuum of Care Needs for TBI Survivors

Corrigan et al (2004) – 40% of people hospitalized w/ TBI had at least 1 unmet need for services one year after their injury.

Most frequent being: memory/ problem solving, managing stress/ emotional upsets, controlling temper, improving job skills.



Dr. Geoffrey Manley, Neurosurgeon UCSF -
“We’ve gotten much better at getting people to survive, but we have a lot of work to do to help people recover.” (SF Chron)

Research Demonstrates Needs...

- Post-TBI = high rates of psychiatric dx (depression, anxiety, bi-polar sx, etc)
 - (VanReekum, 1996, Journal of Brain Injury)
- Unemployment, poverty, marital changes = increased disability post injury
 - (Seel, 2003, multi-center study, National Institutes on Disability & Rehabilitation)
- Re-hospitalization @ 5 yrs post (high rate for mental health issues)
 - (Humphreys, 2013, literature review)
- Activity based goal-oriented treatment = + outcomes
 - (Novakovic-Agopian, 2010, Journal of Head Trauma Rehabilitation)

Survivors needs from our experience...

- A place to belong and be with others who understand
- Affordable therapies to continue to rehabilitate
- Tailored approach to their specific injury and challenges
- Help finding resources in the community
- Genuine caring and compassion from professionals
- Feeling a sense of purpose and connection
- Services that meet them where they are and that challenge them to grow and reach their highest potential
- Education about their injury and rehabilitation
- Support for family and loved ones whose lives have changed as well and also who may not understand the needs of their injured loved one

Some Gaps In Care & Support...

- Housing, esp for brain injury specific support
- Case management/resource assistance
- Employment training and assistance
- Continued affordable treatment/therapies
- Socialization, support and community involvement
- Services and consultation for caregivers/family
- Continued rehabilitation provided with professionals trained in acquired brain injury
- Dr. Wilson:
 - Psychotherapy with ABI understanding
 - Services that offer inclusion of CG's with survivor



If you want to make God laugh
tell Him about your plans.
- Woody Allen



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Challenges Caregivers Face...

- 'People plan, God laughs' - Thrust into a new life without a roadmap
- Lack of knowledge about brain injury
- Economic, legal, insurance complications
- Limited medical resources and help once home
- 24-7 nature of caregiving
- Changing landscape and ongoing advocacy needed for loved one
- Feeling lonely, overwhelmed and undone – others do not understand
- Not losing 'self'
- Physical, cognitive, psychological changes of loved one over time
- Accepting how their loved one has changed

What Caregivers Tell Us They Need...

- To connect with others who understand – who “get it”
- Affordable therapies for their loved one to continue to rehabilitate
- Respite and time away
- Help finding resources in the community
- Genuine caring and compassion from professionals
- Education about brain injury, what to expect, how to support their loved one with the challenges faced, coping strategies, understanding the ‘invisible’ injury
- Services that are designed to support caregivers – to not be forgotten as the focus is on the ‘patient’ – CG’s lives have changed as well
- Case management/treatment planning help – what to plan for short and long-term and help researching and accessing service
- Financial assistance to support need for hired help, continued therapies, housing, legal issues, etc

Caregivers Insights & Guidance...

- Do 'whatever' you can to sustain yourself as you care for your loved one
- Acknowledge your emotions (frustration, sadness, exhaustion, etc)
- Join a group and create relationships with peers/other caregivers (Schurig Center, UCSF/SF General, Love Your Brain, etc)
- Ask for help – seek out professionals for guidance
 - Consult legal counsel for disability claims/info, estate planning, conservatorship, medical directives, etc
 - Utilize ombudspeople to help advocate for loved in the medical system
 - Contact a facility expert, social worker, case manager when deciding to transfer institutions for medical care or living situations vs doing it on your own
- Accept the limitations of the 'allopathic' medical system
- Seek out education to learn about injury, what to expect, tips for coping
- Allow family and friends to support you
- Give back in some way – gives higher purpose to the trauma you've had
- Be grateful – for the remarkable healing and the medical help received
- Laugh often, spend time with animals and children, don't lose yourself

CAREGIVER BURNOUT

“**Caregiver burnout** is a state of physical, emotional and mental exhaustion. It may be accompanied by a change in attitude, from positive and caring to negative and unconcerned. Burnout can occur when caregivers don't get the help they need, or if they try to do more than they are able, physically or financially. Many caregivers also feel guilty if they spend time on themselves rather than on their ill or elderly loved ones. Caregivers who are "burned out" may experience fatigue, stress, anxiety and depression.”

CARING FOR CAREGIVERS

- 1. Listen
- 2. Don't offer unsolicited advice
- 3. Give space (Space the “vital frontier”)
- 4. Don't give them guilt trips.
- 5. Have empathy.
- 6. Don't judge.
- 7. Do laugh.

Today's Caregiver, Lisa Lopez, Seven Essential Do's and Don'ts for People Caring for Caregivers

CHRONIC EFFECTS POST-CONCUSSION SYNDROME

“The main finding from our scoping review relates to the incidence of persistent cognitive impairment in individuals with chronic stage mTBI following a single concussion. The findings from our scoping review **do not support the conclusions of previous reports that a single mTBI leads to PCS in 15% of individuals in the chronic stage injury**, and that the other 85% will see resolution of symptoms during the acute phase.

McInnes K, Friesen CL, MacKenzie DE, Westwood DA, Boe SG (2017)

Mild Traumatic Brain Injury (mTBI) and chronic cognitive impairment: A scoping review. PLoS ONE 12(4): e0174847.



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RISK OF DEMENTIA FROM TBI

Is there any connection between Traumatic Brain Injury and Dementia?

The researchers found that any medical history of head injury more than doubled both the risk of developing Alzheimer's disease and the chances of developing non-Alzheimer's dementia, even after adjustment for the effects of age (Neurology 2000;55:1158-66).

- Over the last three decades, research has connected moderate and severe traumatic brain injury to an increased risk of getting Alzheimer's disease or another dementia years later.
- According to a study, the higher the severity of the head injury, the higher the Alzheimer's risk. Seniors with a history of moderate brain injury had a 2.3 times greater risk of developing Alzheimer's than seniors with no TBI history.
- Furthermore, those with a history of severe brain injury had an even higher (about 4.5 times) risk. Some other studies (but not all) have also suggested a similar connection between moderate and severe TBI and increased risk.

Effects of Concussion/ mTBI

Neurosurgery, September 1981, Rebecca Rimel, et al

University of Virginia Study

The authors studied 538 patients with history of mTBI, LOC of 20 minutes or less. ED treatment or hospitalization of less than 24 hours. GCS score of 13-15.

They found on follow-up with 424 of them 3 months later:

- 79% complained of persistent headaches.
- 59% described memory problems.
- Of those who were employed before, only 34% were employed now.

BRAIN HEALTH CHECKER

<https://www.alzheimersresearchuk.org/brain-health/check-in/>

- People can take 12 steps to reduce their risk of getting dementia, according to a new brain health checker.
- The vast majority of people are not doing enough to ward off dementia in later life, according to **Alzheimer's Research UK**.
- The charity said it wanted to empower people to make choices to help reduce their odds of developing dementia, saying that dementia is the “most feared consequence of ageing”.
- Some 40% of dementias are thought to be linked to lifestyle factors, which can be modified to reduce a person's risk.
- Dementia is now the most feared consequence of ageing so people are wanting to know what they can do about their risk

Prof Jonathan Schott

BRAIN HEALTH CHECKER

<https://www.alzheimersresearchuk.org/brain-health/check-in/>

Question 1 of 3

1. How often do you do activities that challenge your brain?

(This could include challenging work, reading, playing games, doing puzzles, learning a language, playing an instrument, etc)

- Never
- Occasionally
- Most Days
- Every Day

BRAIN HEALTH CHECKER

<https://www.alzheimersresearchuk.org/brain-health/check-in/>

Question 2 of 3

2. On average, how many hours of quality sleep do you think you get a night?

(Lots of us wake up during the night and still get a good night sleep. Quality sleep means you do not wake up too frequently and do not struggle to get back to sleep.)

- 1 to 3 hours
- 4 to 6 hours
- 7 or more hours

BRAIN HEALTH CHECKER

<https://www.alzheimersresearchuk.org/brain-health/check-in/>

Question 3 of 3

3. Do you regularly take steps to look after your mental wellbeing?

(This could include taking time out for hobbies and activities you enjoy or talking with friends and family. Anything that helps you feel happier, healthier, and more relaxed.)

- YES
- NO

<https://www.alzheimersresearchuk.org/brain-health/check-in/>

- – Getting at least seven hours of sleep a night
- – Regularly challenging the brain
- – Looking after mental wellbeing
- – Staying socially active
- – Looking after your hearing
- – Eating a balanced diet
- – Staying physically active
- – Quitting smoking
- – Drinking responsibly
- – Keeping a healthy level of cholesterol
- – Maintaining healthy blood pressure
- – Managing diabetes as well as possible

COUNT YOUR DAILY STEPS

“In this cohort study involving 78,430 subjects in the UK, with 6.9 years of follow-up, a higher number of steps was associated with a lower risk of all-cause dementia. The findings suggest that a dose of just under 10,000 steps per day may be optimally associated with a lower risk of dementia. Steps performed at higher intensity [i.e., more purposeful or brisk walking] resulted in stronger associations.”

JAMA Neurology | Brief Report, Sept. 6, 2022, Borja del Pozo Cruz, Ph.D., et al
Association of Daily Step Count & Intensity With Incident Dementia in 78,430 Adults Living in the UK.”

KEEPING THE BRAIN HEALTHY

10 Ways to Boost Your Cognitive Fitness and Longevity

- Exercise to improve cognitive function
- Read Actively
- Take up a new hobby (Gardening, language)
- Solve different types of puzzles
- Join community organizations (e.g., BORP) take a class
- Play board games
- Visit museums, historical sites, take a workshop.
- Reduce stress and address depression
- Join in activity - a class at the Schurig Center

by Dennis Kravetz, Ph.D., Huff Post Contributor 7/02/2013



**A Community of Support for
Survivors & Caregivers**



**SCHURIG
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For Brain Injury Recovery

Accidents are part of lives, and though we cannot undo those events, we can provide a recovery based on a renewed sense of hope, purpose and support!

Our Referral Process



- Call us at (415) 461-6771 x100
- We complete an intake
- Then we make referrals to one of our center's services and/or help you in find community resources
- Visit SchurigCenter.org for a directory of services and resource

Happy to Answer Your Questions...



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