

NEXT STEPS:

A Guide for Families After a Dementia Diagnosis

Caregiver Connections

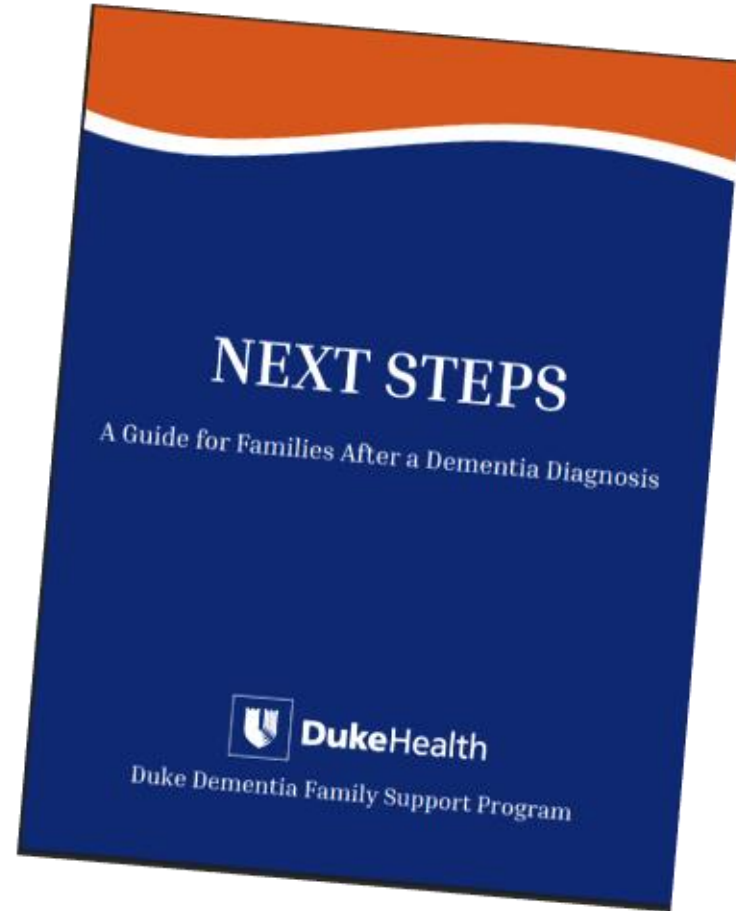
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Duke Dementia Family Support Program

Introduction

- **You're not alone:** Feeling overwhelmed is common — we're here to help
- **A roadmap:** Key next steps to make the path forward clearer
- **One step at a time:** Take what's helpful now; revisit the rest later



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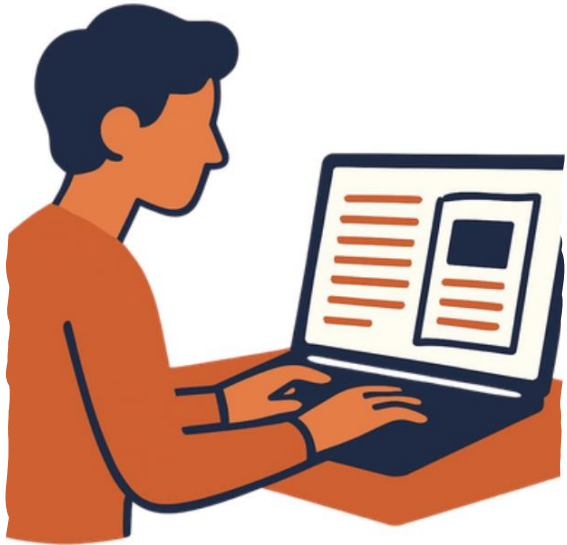
Take Time to Breathe

- Mixed emotions are normal after a dementia diagnosis
- Embrace acceptance
- Try meditation and relaxation exercises



Sample relaxation technique: 5-4-3-2-1 Grounding Exercise

Educate Yourself



- Learning will take time
- Choose the best media for you
- How might understanding dementia and what to expect help?
 - Will help you communicate with healthcare providers
 - Informs decision making
 - May ease your coping

Telling Others

- Opens door for more support
- Keeping secrets is exhausting
- Helps maintain engagement in activities
- Enhances safety
- Reduces stigma and increases public awareness



Legal Matters



- For Health Care Matters – Advance Directives
 - Health Care Power of Attorney
 - Advance Directive for a Natural Death (Living Will)

Legal Matters

Forms to Complete with a Physician

HIPAA Authorization Form

DUKEHEALTH
 AUTHORIZATION FOR RELEASE OF INFORMATION
 "If for oral communication, fill out Verbal Release of Information Authorization"

PART A: PATIENT INFORMATION
 Legal Patient Name (Required): _____ Preferred Name: _____
 Date of Birth: _____ Medical Record #: _____ SSN (Last 4 Digits): _____
 Email: _____ Phone: _____
 Address: _____ City: _____ State: _____ Zip: _____

PART B: PERSON OR COMPANY WHO WILL RECEIVE INFORMATION
 Self (Same Info As Above) _____ Phone: _____
 Person or Entity: _____
 Email: _____ Fax: _____
 Address: _____ City: _____ State: _____ Zip: _____

PART C: INFORMATION TO BE RELEASED (Check All That Apply)
Treatment Location:
 Duke University Hospital Duke Raleigh Hospital, a campus of Duke University Hospital All Duke Health Enterprise Entities
 Duke Regional Hospital Duke Clinic (Specify Location): _____
 Duke Lake Norman Hospital

Treatment Date(s): Last 2 years of active treatment will be provided unless specified.
 From _____ to _____ (Please Be Specific) **Or** All Treatment Dates

Records or Information: If referring to a provider, an Abstract/Summary of records will be sent unless otherwise marked below.
 Abstract/Summary (includes items in bold) **Or** Inter Record (does not include billing or imaging) Billing Records
 Discharge Summary Consultation Report Emergency Department Record Radiology Images (CD only)
 History and Physical Operative/Procedure Report Physical/Occupational Record Cardiology Images (Echo, Cath Lab)
 Clinic Visit Laboratory Reports Immunization Record Neurology Images (EEG)
 Radiology Reports Pathology Reports Other Imaging

PART D: PURPOSE OF REQUEST
 Personal Legal Insurance Continuation of Care Other (specify): _____

PART E: FORMAT AND DELIVERY OF INFORMATION (Select One Option)
Electronic Delivery
 My Duke Health (Patients Only) Encrypted Email (Provide in Part B) Mail Delivery
 Portal (Attorney/Insurance) Fax (Provide in Part B) CD (Charger may apply)
 Paper (Charger may apply)

PART F: REVIEW AND APPROVAL
 I understand that the information to be released may include reference to sensitive information related to mental and behavioral health, genetic testing, HIV/AIDS or other communicable diseases. I specifically approve the release of the following information that has been marked as sensitive and/or restricted (check all that apply):
 Mental and Behavioral Health Genetic Testing

I understand that I may revoke this Authorization in writing at any time, except to the extent that action has already been taken in response to the Authorization. I understand that the information released pursuant to this Authorization may be re-disclosed by the recipient and may no longer be protected under federal privacy law. I understand that I may refuse to sign this Authorization. If I do not sign this Authorization, Duke Health will continue to provide treatment and seek payment for services provided. Duke Health may charge a fee for providing the information specified above.

This Authorization will automatically expire one year from the date signed below unless revoked or another date or event is written here:

Signature of Patient/Patient Representative _____ Printed Name _____ Date _____
 Relationship (if not signed by Patient) _____ Phone Number (if different from above) _____

If you are not the patient or the parent of a minor patient, you MUST attach documentation of your authority to act on behalf of the patient (Power of Attorney, Court Order, Legal Guardian Documentation, Executor/Administrator Documentation)

SEND COMPLETED FORM TO ONE OF THE FOLLOWING:
 Fax: 919-620-5165 ;DU@response@duke.edu; For Questions Call: 919-684-1700;
 Duke University Hospital - HIM, DUMC Box 3016, Durham, NC 27710

Do Not Resuscitate Order (DNR)

STOP DO NOT Resuscitate

Effective Date: _____
 Expiration Date, if any _____
 Check box if no expiration

DO NOT RESUSCITATE ORDER

Patient's full name _____

In the event of cardiac and/or pulmonary arrest, no resuscitative efforts at cardiopulmonary resuscitation of the patient SHOULD BE ATTEMPTED. This order does not affect other medical care that may be provided.

I have documented the basis for this order and the consent required by the NC General Statute 90-21.17(a)(2). The patient's records.

Signature of Physician/Physician Assistant/Nurse Practitioner _____
 Printed Name of Attending Physician _____
 Address _____
 City, State, ZIP _____
 Telephone Number (office) _____
 Telephone Number (emergency) _____

Do Not Copy Do Not Alter

Medical Order for Scope of Treatment (MOST)

Medical Orders for Life-Sustaining Treatment (MOLST)

THE PATIENT WANTS TO BE CARED AS FOLLOWS (PLEASE PRINT) TO PREVENT CARE WITHING THE PHYSICIAN OFFICE & HOME:

DO NOT RESUSCITATE (DNR) OR OTHER LIFE-SUSTAINING TREATMENT (OLST)

SECTION A - Advance Directive: What the Patient May Be Able to Do in the Event of an Emergency

I am able to make my own decisions about my care.

I am unable to make my own decisions about my care. I have designated a healthcare proxy to make decisions for me. My healthcare proxy is: _____

SECTION B - Current or Previous Life-Sustaining Treatment

I am currently on life-sustaining treatment. I want to continue with life-sustaining treatment. I want to stop life-sustaining treatment. I want to be kept on life-sustaining treatment until I am able to make my own decisions about my care.

SECTION C - Patient's Signature for Sections A and B

Signature of Patient/Healthcare Proxy _____ Date _____

SECTION D - Physician's Signature

Signature of Physician/Physician Assistant/Nurse Practitioner _____ Date _____

Legal Matters

- For Finances
 - Durable Power of Attorney
 - Standard Will
 - Living Trust (if necessary)



Signs of Trouble Managing Finances

- Trouble counting change, paying for a purchase, calculating a tip, or understanding a bank statement
- Unopened and unpaid bills
- Lots of new purchases on a credit card bill
- Unexpected new merchandise in the home
- Money missing from the person's bank account

National Institute on Aging

Protect Your Finances



- Get organized
- Simplify
- Add oversight
- Monitor your finances
- Limit access gradually
- Guard against identity theft and scams

Support & Self Care



- Consider support systems for *YOU*
 - Support groups
 - Individual counseling
 - Find your people (friends, family, etc.)
- Consider self care
 - Create a list of ways others can be helpful
 - What fills your cup? Can you create meaningful “You Time?”

Build Your Team

- The team will change
- Assess what is needed today
 - What areas are creating the most stress?
 - What need is unmet?



Possible Team Members

- Primary care provider
- Memory care specialist
- Social worker
- Elder law attorney
- Financial advisor
- Geriatric care manager/
Aging Life Care Professional
- Therapist or counselor
- Speech pathologist
- Physical therapist
- Occupational therapist
- Home care provider
- Adult day program
- Friends & family
- Faith community
- Neighbors
- Support group

Balance Safety & Autonomy

The time to think about safety issues is before there's a problem.

— Kris Herfkens, PhD



Safety: Driving

- Begin the conversation early
- Involve the doctor
- Consider a driving contract
- Observe behavioral signs
- Monitor driving
- Arrange for a driving evaluation



Balance Safety & Autonomy

- Emergency identification
- Home Safety
 - Medication management
 - Online safety
 - Staying alone
 - Owning guns



Have a Backup Plan

If you cannot, who will?



Long-Term Care Options

In home

- Companion & personal care
- Home health

In community

- Day programs
- PACE
- Enrichment programs

Residential

- Assisted living
 - Adult care homes
 - Memory care
 - Family care homes
- Nursing homes
- CCRCs

Paying for Long-Term Care

- Medicare (limited circumstances)
- Long-term care Medicaid
- State/county special assistance
- Long-term care insurance
- Veterans' benefits
- Paying out of pocket (self-insuring)



Consider a Research Study



Scan the QR
Code to
Access the
Digital Guide



Contact Us

Duke Dementia Family Support Program

Phone: 919-660-7510

Email: DDFSP@duke.edu

Website: dukefamilysupport.org

Education · Support · Engagement

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