North Carolina Department of Health and Human Services
Division of Aging and Adult Services
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Michael F. Easley, Governor
Carmen Hooker Odom, Secretary

Dennis W. Streets
Director

August 31, 2006

Dear *Candlelight Reflections* Participant,

I am very excited about the upcoming 2006 *Candlelight Reflections* initiative—a partnership of the NC Family Caregiver Support Program and the NC Alzheimer's Support Network. This type of unified, collaborative approach will help raise public awareness and strengthen statewide efforts to support family caregivers of persons with debilitating conditions, including those living with Alzheimer's disease and related disorders.

The enclosed *Candlelight Reflections* toolkit was developed by a team of dedicated professionals from organizations across the state. I hope you will find these suggestions and resources helpful and that they will serve as valuable tools to aid in developing your own local *Candlelight Reflections*.

If you need more information or further assistance, please contact any of the following *Candlelight Reflections* supporters:

- ✓ The *Candlelight Reflections* founders— NC Alzheimer's Association:
  Eastern North Carolina Chapter (919) 832-3732 or www.alznc.org
  Western Carolina Chapter (704) 532-7392 or www.alz-nc.org;
- ✓ Duke Bryan Alzheimer's Disease Research Center African-American Community Outreach Program 1-866-444-2372; and/or
- ✓ Your local Area Agency on Aging Family Caregiver Resource Specialists: a list can be found at www.dhhs.state.nc.us/aging/fcaregr/fcjobs.htm or call the NC Division of Aging and Adult Services at (919) 733-3983.

We greatly appreciate your commitment and dedication to help make the 2006 *Candlelight Reflections* a success and for investing the time and effort *to honor, hope, and remember* all family caregivers and Alzheimer's families throughout North Carolina.

Sincerely,

Dennis W. Streets

Dennis W. Streets

Location: 693 Palmer Drive, Raleigh, NC 27603 • State Courier No. 56-20-02
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NOVEMBER

National Alzheimer's Disease Awareness Month and National Family Caregiver Month

We invite you to attend *Candlelight Reflections* on November 1, 2006.

to honor,
hope, and
remember

Candlelight Reflections will honor all those affected by Alzheimer's disease and related disorders as well as all family caregivers. We invite communities and organizations across the state to participate in and/or host *Candlelight Reflections* on the first of November 2006.

Families provide at least 80% of all long term care—an enormous contribution to the long term care system. In North Carolina, 1.7 million adults are caring for an older person—more than 28% of the adult population. Over 40% of North Carolina caregivers take care of someone with a memory disorder like Alzheimer's disease. Their "caregiving career" will last an average of 8 years but may be as long as 20.

One in ten Americans say that they have a family member with Alzheimer's and one in three know someone with the disease. Alzheimer's disease is now the fifth leading cause of death in the United States following heart disease, cancer, cerebrovascular disease, and chronic lower respiratory diseases.

In North Carolina alone, an estimated 132,000 have the disease. Over the next 20 years, this number is expected to increase to 253,000 residents. More than 70% of people with Alzheimer's disease live at home and are cared for by family and friends.

Please join us on November 1st through *Candlelight Reflections*. Our hope is that the flame of each candle will enlighten our communities and state leaders as to the growing numbers of those living with Alzheimer's and the critical need to support all family caregivers.

Please contact your local Alzheimer's Association Chapter, regional Area Agency on Aging and/or the Duke African-American Outreach Program for more information on *Candlelight Reflections* and other National Alzheimer's Disease Awareness Month and Family Caregiver Month activities and programs.

Eastern North Carolina Chapter: **(919) 832-3732** or **www.alznc.org**
Western Carolina Chapter: **(704) 532-7392** or **www.alz-nc.org**
Duke Bryan Alzheimer's Disease Research Center (ADRC) African-American Community Outreach Program (AACOP): **866-444-2372**
A list of local Area Agency on Aging Family Caregiver Resource Specialists can be found at **www.dhhs.state.nc.us/aging/fcaregr/fcjobs.htm**
or call the NC Division of Aging and Adult Services at **(919) 733-3983**.

Organization of

Candlelight Reflections

to honor, hope and remember...

alzheimer's association®
nc family caregiver support program

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Candlelight Reflections

Wednesday, November 1, 2006

A Statewide Event to Honor All the Lives Affected by Alzheimer's Disease and Related Disorders and All Family Caregivers.

> *When you light your candle tonight, light it not only in memory and support of your loved one, but light it in hope and commitment as well.*
>
> — Chris Adkins, in honor of his father

Candlelight Reflections is a beautiful and moving experience. It can serve many roles—heightening public awareness of Alzheimer's disease and caregiver issues, honoring and supporting family caregivers and individuals with dementia, and strengthening statewide advocacy efforts.

Several years ago, the Eastern North Carolina and Western Carolina Alzheimer's Association Chapters created *Candlelight Reflections* to bring together Alzheimer's families, friends, and supporters. This year, in an effort to further increase awareness about dementia and its effect on families, the NC Alzheimer's Support network is joining the NC Family Caregiver Support Program to honor all families and friends taking on the role of caregiving and/or living with dementia. *Candlelight Reflections* will be a momentous beginning to both National and NC Alzheimer's Disease Awareness Month and Family Caregiver Month.

Candlelight Reflections can:

- build awareness in the community about the valuable contributions and unique needs of family caregivers;
- help educate the public about Alzheimer's disease and related disorders, dementia care, and available support services;
- elicit support for state and federal legislation to strengthen support for family caregivers;
- encourage positive changes in the workplace to support caregiving families and individuals with dementia;
- create opportunities for volunteer recruitment as well as "neighbor helping neighbor" efforts;
- motivate people in the community to become more involved in local Alzheimer's Association Chapter activities and other ways to support family caregivers; and
- provide public relations materials and educational resources to local media, faith communities, and other entities who can share the message.

We challenge you to think broadly when planning the groups and individuals you will contact for participation, sponsorship, planning assistance, and attendance at your local event. Families, individuals, corporations, small businesses, public officials, educators, human service agencies, faith communities, ministerial associations, health clubs, healthcare professionals, civic and social club, etc., are among the vast possibilities.

People are encouraged to participate as a means of demonstrating respect, concern and support for family caregivers and all the lives affected by Alzheimer's disease and related disorders.

Candlelight Reflections

Organization of
Candlelight Reflections

Getting Started—What will you need?

- **SITE COORDINATOR**

  — form a working committee (or a committee which will select a coordinator)

- **LOGISTICS PERSON**

  — find a location
  — get permits if needed
  — secure sound system
  — secure adequate parking

- **RESOURCE DEVELOPER**

  — secure contributions for the event and its promotion

- **PUBLIC RELATIONS PERSON**

  — contact local media to secure maximum coverage and attendance

- **COORDINATOR OF VOLUNTEERS to:**

  — distribute promotional materials and event reminders
  — stuff envelopes
  — distribute flyers
  — make phone calls
  — send e-mails, etc.

The following support information
will help you develop your
Candlelight Reflections

Pulling It All Together: Logistics to Consider

You will get better turnout results and more local participation and support if you allow at least 60 days lead time for your event. As you develop the details for your *Candlelight Reflections*, it will help to consider the following:

- ✓ **Date and Time:** November 1, 2006 at approximately 6:00-6:30 p.m. (The start and end time may vary due to local considerations.) ***The actual lighting of the candles will take place at 7:00 p.m. across the state.***

- ✓ **Location:** Possibilities may include churches, hospitals, civic buildings, schools, town squares, or any site which is easily accessible by large numbers of people.

- ✓ **Permits**: Check with local officials regarding permits which may be necessary to obtain for the event.

- ✓ **Sound System:** Guest speakers will probably require microphones. Check with available local resources and volunteers who are familiar with the operation of the sound system you plan to use.

- ✓ **Parking/Safety:** Since the events will be at night, check to make sure that sites have ample and secure parking nearby. Enlisting volunteers, especially for public areas, will aid attendees to park quickly and safely.

- ✓ **Rain Contingency:** Planning for bad weather is important. For outdoor events, alternative locations should be secured in the event of rain or inclement weather. If more than one organization is conducting *Candlelight Reflections* in your area, coordinating with planners at churches, synagogues, mosques, schools, hospitals, etc. for such possibilities could make a significant difference in turnout.

- ✓ **Materials**: Try to solicit local merchants, community leaders or other organizations for candle donations. List them in programs as sponsors, friends, supporters, etc. They will get a tax write-off and free advertising. Additionally, you may want to have colored lapel ribbons, buttons, flowers, or some other item to serve as reminders/advertising tools before your event, as well as to hand out to attendees during the service.

- ✓ **Funding**: It is probably to your advantage to get a head start to find funding sources to make your event a success. You will need money/donations/commitments of gifts for all your preliminary materials and for securing the site/permits. Find local merchants, community leaders, religious and civic organizations, etc. to help in the costs of printing programs, postage for mailing invitations, candles for the service, phone calls to make all arrangements, advertising in local newspapers, and Public Service Announcements (PSAs) on local radio/television programming.

- ✓ **Work with Local Media**: See notes on **Promotion** on the following page.

- ✓ **Be Creative**: You have a lot more resources than you may realize. Making early phone calls and visits to potential supporters can make it enjoyable and meaningful for you and all involved.

Promotion

November is National Alzheimer's Disease Awareness Month and Family Caregiver Month. To kick off the month of recognition, the North Carolina Alzheimer's Support Program and Family Caregiver Support Program are promoting statewide *Candlelight Reflections*.

Candlelight Reflections will be a joint effort to heighten public awareness about Alzheimer's disease and related disorders and the need to recognize and support family caregivers. This event will be a special time to pay respect to those who have died of Alzheimer's as well as honor those individuals and families who are presently living with the disease. It will also be an important time to express gratitude and appreciation to family caregivers for their invaluable contributions.

Each county and/or individual community is strongly encouraged to host *Candlelight Reflections* on Wednesday, November 1, 2006 beginning around 6:00-6:30 p.m. **The actual lighting of the candles will take place at 7:00 p.m. across North Carolina.**

An event of this magnitude should have greater impact on state policy makers and the general public. It will also create unique opportunities to connect with others facing similar life challenges.

How you promote and coordinate your local program as well as the frequency and type of promotional activities will have a significant impact on the success of your event.

Promotional efforts may include:

- ✓ **Press Releases:** Send to radio and TV stations and daily and weekly newspapers. Use the template Public Service Announcement (PSA) for general information about Alzheimer's disease and family caregivers, then personalize the PSA with specific details.
- ✓ **Special Interest Stories:** A local family or individual may wish to tell their own experience of caregiving and/or living with dementia. If local newspapers are well staffed, attempt to get a staff writer to help write a feature article or possibly a series prior to and during the month. The series could include a variety of caregiving situations and personal stories (e.g., Alzheimer's disease, stroke, diabetes, etc.)
- ✓ **Frequent Announcements**: Ask churches, synagogues, mosques, etc. to announce the event at services and include it in weekly programs. Those religious institutions holding a Wednesday evening service may want to consider incorporating *Candlelight Reflections* on November 1st. Contact other local organizations with newsletters, web sites, listserv, etc. to assist in promoting the event.
- ✓ **Support Groups:** Ask facilitators or local support groups to be sure that all members know about the event and can help recruit participants.
- ✓ **Spread the Word:** Send updated information to the Alzheimer's Association Chapter offices to post on web sites and use in newsletters.
- ✓ **Statewide Flyer:** In the supplied statewide flyer, there is space to insert specific site and event details.
- ✓ **Be Creative**: If you find a marketing and/or outreach strategy that is working well, please let us know so we can share your ideas with others across the state.

Maximize Turnout: Who to Invite

Basically, ***EVERYONE!*** But here's a list which will help you get started.

- ✓ **Local Alzheimer's Support Groups and other Caregiver Support Groups**
- ✓ **Directors and Personnel of Long Term Care Facilities**
- ✓ **Leaders and Members of the Faith Community**
- ✓ **Health and Human Service Professionals** (i.e., Adult Day Service Programs, Home Care and Hospice Agencies, Senior Centers, etc.)
- ✓ **Local Aging and Adult Services Staff**
- ✓ **City/County Government Officials**
- ✓ **Aging Advocates**
- ✓ **Civic and Professional Groups**

Pilot Club	American Business Women's Association
Rotary Club	Junior League
Kiwanis	Retired Government Employees
Police/Firemen	Lawyers/Accountants
Girl Scouts/Boy Scouts	Many others (share ideas)

- ✓ **Local organizations may offer to serve as co-sponsors.** Encourage as much collaboration and community involvement as possible.
- ✓ **For each person or group you contact, be sure to encourage that *Everyone Bring a Friend.***
- ✓ **Consider Respite Care**: Family members may wish to attend but are obligated to stay home and care for a loved one. If respite care can be arranged, let them know the service is available as a way of supporting and honoring all of their caregiving efforts.

Program

We encourage all community events to follow a similar program so that candles will be lit across the state at the same time (7:00 p.m).

The following is a suggested program format:

- ✓ **Inspirational music before event as people arrive**

- ✓ **Welcoming remarks**
  (a local personality, mayor, civic leader, Alzheimer's Association staff, AAA Family Caregiver Resource Specialists, etc.)

- ✓ **An update** on Alzheimer's and family caregiver information and/or programs along with a description of the services available from local Alzheimer's Association Chapters and Family Caregiver Support Programs

- ✓ **Governor's Proclamations** (to be distributed upon release)
  (ask mayor, civic leader, minister to read)

- ✓ **Poem Reading** (i.e., "Hands All Around Me" or "Remember Me"—you may consider asking a person with early dementia or a caregiver to read)

- ✓ **Optional Prayer** (i.e. "The Alzheimer's Prayer" or "The Caregiver's Prayer")

- ✓ **The Lighting of Candles 7:00 p.m.**

- ✓ **Optional Naming Ritual**: as candles are being lit, people may want to say names aloud—individuals, caregivers and/or families— as a way of honoring them and/or asking that they be remembered in your thoughts and prayers

- ✓ **Inspirational Music** as the event closes and everyone leaves.

Candlelight Reflections

Follow-Up

Writing or calling to thank those involved in the promotion, coordination, and production of your event will encourage future involvement and interest.

- ✓ **Committee Members**
- ✓ **Your Honorary Chairperson(s)**
- ✓ **Volunteers**
- ✓ **Media Staff**
- ✓ **Sponsors and Supporters**
- ✓ **Site Host(s)**
- ✓ **Event Speakers**
- ✓ **Special Guests**
- ✓ **Individuals and Family Members** who took the time to participate.

Consider placing a ***"Thank You Letter"*** *in local newspapers, local radio calendar event shows, etc.*

Alzheimer's Prayer

Great Creator,
We pray.

For those who have died of Alzheimer's disease
— Peace —

For those who now struggle with Alzheimer's disease
— Dignity and Comfort —

For Families, Caregivers, Friends, and Supporters
— Compassion and Courage —

And for those who seek the cause, cure, prevention,
and treatment of Alzheimer's disease
— Our Sincerest Thanks —

Please accept our earnest and humble prayer.

Amen

Candlelight Reflections

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Prayer of St. Francis of Assisi

Lord,
Make me an instrument of your peace.
Where there is hatred, let me sow love;
where there is injury, pardon;
where there is doubt, faith;
where there is despair, hope;
where there is darkness, light; and
where there is sadness, joy.

O Divine Master,
Grant that I may not so much seek to be consoled as to console;
to be understood as to understand;
to be loved as to love.
For it is in giving that we receive;
It is in pardoning that we are pardoned;
And it is in dying that we are born to eternal life.
Amen

A Caregivers Prayer

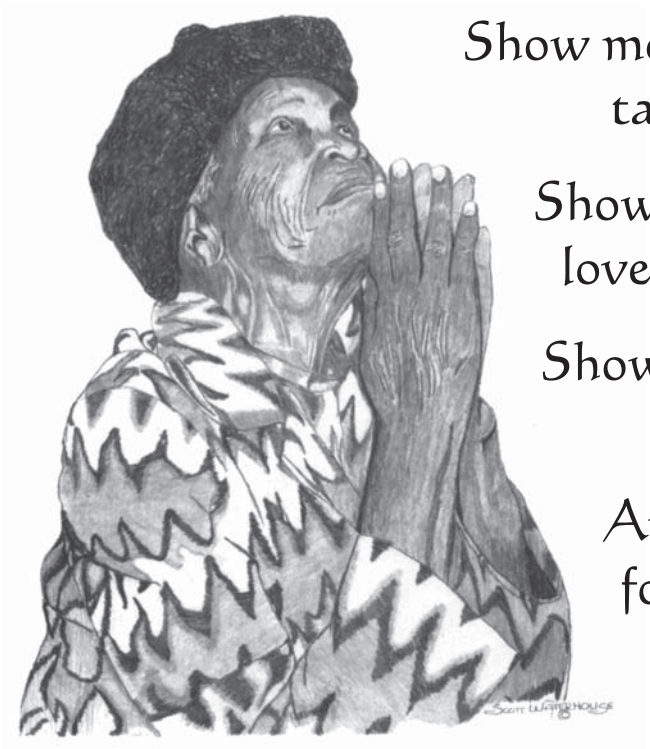
by W. Scott Waterhouse

Lord, Show me the strength within me because I am very tired,

Show me patience to care for the one I love,

Show me peace of mind as I struggle through each day and night,

Show me the joy in the little things my loved on does to help me out,



Show me love when anger wants to take over my thoughts,

Show me compassion when my loved one becomes frustrated,

Show me hope when I can see no hope,

And Lord, show me kindness for those who care about me.

Amen

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Candlelight Reflections

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A Prayer from a Caregiver

Dear Father in Heaven,
Please help me today
To find courage and strength
And to watch what I say.

Make me gentle and kind
And have a big heart
Give me endurance, fortitude,
Be merciful and smart.

I'm asking for some
Who can't fold hands in prayer;
But they are your children
And know that you're there.

Let the ones I care for
Know of my love.
Help them today
From Heaven above.

Asking all this In God's name.

Amen.

Adapted from A Caregiver's Prayer by Shirley Procell

Remember Me

Do not discuss me as if I am not present.
My mind is foggy but my heart is clear.

Do not criticize my imperfections.
If only I could choose to remember even the simplest of tasks.

Do not resent my frequent repetitive questions. I am scared and confused.
Your answers slip from my desperate grasp.

Do not stop loving me because my actions are inappropriate.

Use patience and kindness to remind me of my manners
for they have disappeared with other fragments of my mind.

Do not resent my frequent pacing or attempts to "go home."
This is not my home. Nothing here is familiar or reassuring.
If only I could go home, I would surely find my memory there.

Do not remind me of my recent hurts.
I do not recall that my mate has passed or my house burned to the ground.

Do not speak to me as a child.
I have a lifetime of experiences despite my childlike ways.

Remind me of your name and the place you hold in my life.
I would love to recall, for I feel your love and kindness.

Show me the world—nature, music, art—
for I have forgotten the amazing joy it holds.

Allow me to use the tools that remain,
to hammer out my mark and unwrench my heart.

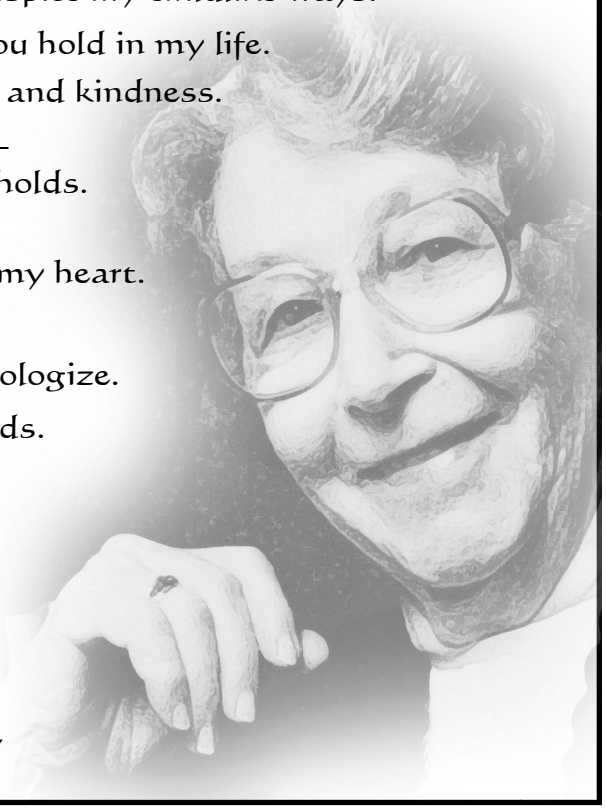
Forgive me for my imperfect past;
If only I remembered, I would surely apologize.

You need not fill our time with many words.
Your presence helps fill my void.

The blame does not lie with you or me.

Love me for who I am now
and the person I used to be.

— J. Al-hafez
June 1997



The following poem was written for all NC caregivers by Kathryn Stripling Byer. This poem is written about a dear friend of the author who was disabled by a stroke in her later life. Willa Mae was a quilter whose spirit lives on in her handiwork. As you read this poem you can see how Ms. Byer uses the quilt and the act of quilting as a symbol of warmth and love and the piece that binds the family together as their lives change.

Hands All Around

was Willa Mae's favorite quilt pattern,
mine too, because I loved each one she quilted,
the way it showed what we must do for each other—
creating the stitchery that love binds, our hands
reaching out to make something to shelter within,
take our comfort inside when the days
and nights seem much too long,
much too difficult to be understood without
making some beautiful thing from our losses and
gifts, our despair and our strength,
all of them gathered up into a pattern
of simple connection, a patchwork
of day by day living our lives,
piecing moment by moment together,
a comfort to pull up around us
when we feel the wind on our faces,
see night falling outside. We shelter inside
what our hands make, remembering what keeps us warm
during dark times, what helps us keep holding on,
reaching out, each to the other, for dear life.

Willa Mae Pressley lived in Cullowhee, NC, a quilter of note and a dear friend of mine. Her mother, Delphia Potts, taught her to quilt when she was a child, and she carried that tradition into the present-day, until disabled by a stroke she was no longer able to hold a needle. Her spirit lives on in her handiwork.

Kathryn Stripling Byer
North Carolina's Poet Laureate

Forget Me Not

Our problems are many and varied.
Our struggles are always uphill.
I'm speaking of our special needs so listen if you will.
I want understanding - not pity.
I wish you could treat me the same
You wouldn't ignore other people.
At least you would ask them their name
I know I can't answer to tell you.
My face may seem empty and dead
My body is twisted - but I am alive.
And there are thoughts in my head.
I will not be shut out from the world.
I'm a person and it is my right
I'm not an object of pity - to be hidden away out of sight.
My children see me through eyes of love.
And not as others do.
They see things I can achieve.
And I wish that you would too.
As I ask you to forget-me-not, I beg you to hear my plea
If I could speak - I would ask you
To please look closer - and see me ....

Hope is not pretending that troubles don't exist.
It is the trust that they will not last forever,
Those hurts will be healed and difficulties overcome.
It is the faith that a source of strength and renewal lies
within to lead us through the dark into the sunshine.

Author Unknown

Still All There?

Henry Walker

(August 31, 2003)

for most of this last decade
Alzheimer's has been taking Mother away
and I've worked to get to her still
and I've worked to figure out what all's happening,

I've written of paranoia and anger,
the loss of mobility—body and word,
I've written also, often, of how much isn't lost,

Well-meaning folks have advised me it's not her here any more,
the insidious alchemy of disease changing her at the core of herself,
but my intuition begs to disagree
as it feels more right to me that self endures strong in her
and that self still is connected to us all
despite the topsy-turvy tumbling of neuronic pathways gone awry,

the more common question to me: "How is she?"
and close on its heels: "Does she still know you?"

and most seem satisfied with no real answer to the first
just some variation and details on "She's fine..."
and the answer to the question seems to tell them
if she's still close enough to be worth care,

even so far along in Alzheimer's cluttered dusk
my wife and I feel who Mother "Is" is still all there
hiding away in dreamy sleep
and when awake without logical, linguistic pathways
to cross the trackless wood
between her "there" and our "here,"

her eyes and heart can still cross with ease
and sometimes still even her words mostly work,

she still knows "who" she is,
it's "where" that scares her,
not knowing exactly "what" is happening,

and if we look to her with our heart
we can still get to a Mother all there.

I Am the Person

I am the person who cannot talk. You often pity me, I see it in your eyes. You wonder how much I am aware of – I see that as well. I am aware of much – whether you are happy or sad or fearful, patient or impatient, full of love and desire, or if you are just doing your duty by me. I marvel at your frustration, knowing mine to be far greater,
for I cannot express myself or my needs as you do.

You cannot conceive my isolation, so complete it is at times. I do not gift you with clever conversation, cute remarks to be laughed over and repeated. I do not give you answers to your everyday questions, responses over my well-being, sharing my needs, or comments about the world about me. I do not give you rewards as defined by the world's standards – great strides in development that you can credit yourself; I do not give you understanding as you know it.

What I give you is so much more valuable – I give you instead opportunities. Opportunities to discover the depth of your character, not mine; the depth of your love, your commitment, your patience, your abilities; the opportunity to explore your spirit more deeply than you imagined possible. I drive you further than you would ever go on your own, working harder, seeking answers to your many questions with no answers. I am your special loved one who cannot talk.

I am your special loved one who cannot walk. The world seems to pass me by. You see the longing in my eyes to get out of this chair, to enjoy life. There is much you take for granted. I want the wholeness of self, I need to go to the bathroom, oh I've dropped my fork again. I am dependant on you in these ways. My gift to you is to make you more aware of your great fortune, your healthy back and legs, your ability to do for yourself. Sometimes people appear not to notice me; I always notice them. I feel not so much envy as desire, desire to stand upright, to put one foot in front of the other, to be independent. I give you awareness. I am your special loved one who cannot walk.

I am your special loved one who is cognitively impaired. I don't learn easily, if you judge me by the world's measuring stick, what I do know is infinite joy in simple things. I am not burdened as you are with the strifes and conflicts of a more complicated life. My gift to you is to grant you the freedom to enjoy things as a child, to teach you how much your arms around me mean, to give you love. I give you the gift of simplicity. I am your special loved one who is cognitively impaired.

I am your special loved one. I am your teacher. If you allow me, I will teach you what is really important in life. I will give you and teach you unconditional love. I gift you with my innocent trust, my dependency upon you. I teach you about how precious this life is and about not taking things for granted. I teach you about forgetting your own needs and desires and dreams. I teach you giving. Most of all I teach you hope and faith.

I am your special loved one.

Author Unknown

Artwork

Candlelight Reflections

to honor, hope and remember...

alzheimer's association®
nc family caregiver support program

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