From childhood to childhood?
Autonomy, dignity and dependence through the ages of life

Harry Cayton
Chief Executive, Alzheimer's Society UK
Alzheimer's can impair everyday skills

People with Alzheimer's disease would be happier if they were treated as infants instead of as adults, researchers have said.

They said dementia could indeed be a form of second childhood, after they found that people with the disease lost essential skills in the same order in which they developed them as a child.

As Alzheimer's progresses, sufferers find it increasingly difficult and then impossible to perform even the simplest everyday tasks - such as washing, eating and dressing - without supervision.

However, a leading charity has said it may be dangerous to treat people who have lived a full life as children.
The headline reads:

‘People with Alzheimer’s would be happier if treated as infants instead of adults researchers have said. Dr Barry Reisberg told the International Psychogeriatric Association that Alzheimer’s patients lose physical and mental abilities in exactly the opposite order that children gain them. Eventually they return to an infant like state, he said.

A spokeswoman from ‘a leading charity, the Alzheimer’s Society’ is quoted as saying this is ‘unhelpful. We don’t think people who have lived a long life and who have a wealth of experience should be treated as children.’

I was really irritated by this report but I began to wonder why. Why was my resistance to seeing dementia as ‘a second childhood’ so strong? Suggesting that people with dementia are like children seems to go against so much that we have been arguing for in care, care that reinforces the autonomy, dignity and especially the adulthood of people with dementia. But it is apparent that this metaphor for the frailties of age is universal. It appears in literature across cultures and epochs and it appears regularly in the way in which carers describe the person they care for. So I came to ask myself if the persistence of the metaphor of a second childhood had insights to give us into how to care for people with dementia and if a comparison of childhood and old age might help us to understand each better.

More than 2,500 years ago, in the fifth century BC the Greek playwright Aristophanes said ‘Men are children twice over’ a sentiment echoed by Shakespeare in Hamlet for instance, ‘They say an old man is twice a child.’

But my title is taken from this quotation from a 19th Century Sioux shaman, Black Elk.
The seasons form a great circle in their changing and always come back again to where they were. The life of man is a circle from childhood to childhood.

Black Elk, 1863 - 1950
We are accustomed in our age of progress to see life as linear, a line moving through time, developing and changing but constantly driving forward. If we are secular rationalists we may see the narrative of our lives as the onward march of the selfish gene but for many with a religious view of the world the concept of the end stage of life being a restoration, a return to home, is a strong one. T S Elliott, the Christian poet wrote
We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time

T S Eliot, Little Gidding, 1942
A sense of loss as well as of homecoming is fundamental to the Judeo/Christian view of the world indeed to many religions. We have lost the innocence of Paradise and must journey through ‘this vale of tears’ in the hope that though experience, or virtue, or perhaps faith, we will ultimately regain it. In this cultural context loss of self has perhaps particular resonance for us.

The sense of self has been key concept in 20th century psychiatry and theories of child development. A secure and balanced sense of self, particularly in relation to the other, is seen as necessary to mental health and social wellbeing. Alienation, disengagement and loss of self have been powerful concepts in psychiatry, philosophy and political theory.

The existentialist view which developed out of the second world war inevitably values autonomy – self governance – most highly as a human goal and sees child development as, to a great extent a process for achieving this autonomy. Indeed the life rituals, the *rites de passage* of many cultures, are symbolic of the achievement of autonomy and often legalise both the right to do ‘adult’ things, for instance marrying without parental consent, and the responsibility before the law for our actions.
This idea of the individual self as having a valid life separate from family and community is I think a late 20th century idea and particularly so in consumerist Western countries. In the UK 29% of people live in single person households. Moreover they see that as desirable a choice one which would be as inexplicable as it is impossible for the peoples of many other cultures.

Some people have suggested that the model of child development developed by the French psychologist Jean Piaget can be applied to people with dementia in reverse. For example Tessa Perrin suggests (Perrin 1997 p 15) that

‘There has been considerable support over the years for the theory that the cognitive losses of dementia reflect (in an opposite direction) the cognitive gains of childhood’

On the face of it I find this difficult. First I’m unable to find much serious literature that does give support to this theory. Secondly while it is true that some of the affective and functional behaviours of people with dementia and children are similar the underlying neurological processes are totally different.

We know that in people with dementia, whether it be vascular disease, or Alzheimer’s or Lewy body, brain cells are dying, chemical neurotransmitters are being disrupted and the brain volume is reducing.

This is not the reverse of the process going on in children’s brains. Children’s brains change very little after birth in neurochemical or structural terms. Modern scanning techniques do show some neurological connections multiplying or changing in some specific areas of the brain but these are not global changes as in dementia. Brains in children are not growing in volume in the way that brains affected by Alzheimer’s are shrinking. There is no increase in the activity of neurotransmitters as the baby develops.

Indeed one of the interesting things we know about babies’ brains is how complete they are even at birth, how they are already ‘hard wired’ as it were for crucial cognitive functions such as language, what Chomsky named deep structure.
Plasticity – the capacity of the brain to change and create new neuronal connections is most apparent in infants but it is not lost entirely in older adults. Old brains can still make new neuronal connections. This is what enables people to recover from strokes or brain injury for example.

Piaget described four phases of child development.
Shakespeare of course had seven ages of man. The psychologist Erik Erikson had eight – to which Naomi Feil, creator of validation therapy, added a ninth to cover the old-old. It is usual to talk of three stages of dementia. Dr Barry Reisberg has described seven. Tom Kitwood had no less than seventeen aspects of malignant social psychology. There are four humours, twelve signs of the zodiac and we have no idea how many angels can dance on the head of a pin!

I say this not to mock but to demonstrate that these are ways of codifying and describing human behaviour and the world we observe, of reducing complexity to enable us to see patterns and understand processes. These lists and tables are academic formulations, they are not facts and they are only part of the truth.
Piaget’s four phases of child development

• Reflexive – responding to external stimuli (first month)

• Sensori-motor – examining the world through sense and movement (until 2 years)

• Representational – construction of mental symbols through parallel play (2 to 4 years)

• Reflective – pattern, order and rule enable social relationships through co-operative play (4 to 7 years)
He validated these phases through experiment and observation. He was careful to explain that they were complex. The driving force for child development is, he showed, play.

Perrin argues that these phases can be used with people with dementia.

For instance using rule based games, such as dominoes or quizzes, in the early stages of dementia progressing, as cognitive powers decline, to sharing in fantasy worlds through conversation, music and drama and ultimately to physical contact, as with small babies, through touching, rubbing, holding and stroking.
Now I think this is sensible in relation to how we might modify our behaviour towards those with progressive dementia. But I find the underlying hypothesis difficult to believe. Piaget saw play as the behavioural building block of education. That is why his views were so attractive to us flowerpower teenagers of the 1960s who grew up to be teachers in the 1970s.

But according to Piaget play is an instinctive and interactive response by a baby to its environment. If people with dementia were retracing their steps back into childhood surely we would see spontaneous play behaviours. It is not that people with dementia don’t respond to playful behaviour by others; they do. It is that, unlike children, play in people with dementia does not seem to be spontaneous or regressive; we don’t see them playing more as they get older.
Reisberg takes functional approach to comparing child development with dementia. He has long been known for his descriptive table of the ‘stages’ of dementia. Recently he has produced in tabulated form a comparison of his ‘stages of dementia’ with some behaviours associated with child development. He calls this ‘retrogenesis’. Which I take it is ‘growing backwards’. Of course it sounds better in ancient Greek.

There are four columns. Reading up from the bottom in the case of child development and down from the top in the case of Reisberg’s scales. If you look at the third column you will see a proposed progression of lost abilities. But are the behaviours of people with dementia really disease determined in this way? Reisberg’s table seems to me to illustrate Kitwood’s ‘malignant social psychology’; seeing the symptoms of dementia as an inevitable, medically determined decline and reinforcing that decline by our response to it. In fact self care, continence, mobility and communication are we know all amenable to intervention, even to improvement with the right care and environment.
## Functional stages in normal human development and Alzheimer’s disease

Dr Barry Reisberg © 1984, 1986, 1996. All rights reserved.

<table>
<thead>
<tr>
<th>Approx age</th>
<th>Acquired abilities</th>
<th>Lost abilities</th>
<th>Alzheimer’s stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>12+ years</td>
<td>Hold a job</td>
<td>Hold a job</td>
<td>3 – INCIPIENT</td>
</tr>
<tr>
<td>8 – 12 years</td>
<td>Handle simple finances</td>
<td>Handle simple finances</td>
<td>4 – MILD</td>
</tr>
<tr>
<td>5 – 7 years</td>
<td>Select proper clothing</td>
<td>Select proper clothing</td>
<td>5 – MODERATE</td>
</tr>
<tr>
<td>5 years</td>
<td>Put on clothes unaided</td>
<td>Put on clothes unaided</td>
<td>6 – MODERATE SEVERE</td>
</tr>
<tr>
<td>4 years</td>
<td>Shower unaided</td>
<td>Shower unaided</td>
<td>“</td>
</tr>
<tr>
<td></td>
<td>Toilet unaided</td>
<td>Toilet unaided</td>
<td>“</td>
</tr>
<tr>
<td>3 – 4.5 years</td>
<td>Control urine</td>
<td>Control urine</td>
<td>“</td>
</tr>
<tr>
<td>2 – 3 years</td>
<td>Control bowels</td>
<td>Control bowels</td>
<td>“</td>
</tr>
<tr>
<td>15 months</td>
<td>Speak 5-6 words</td>
<td>Speak 5-6 words</td>
<td>7 – SEVERE</td>
</tr>
<tr>
<td>1 year</td>
<td>Speak 1 word</td>
<td>Speak 1 word</td>
<td>“</td>
</tr>
<tr>
<td></td>
<td>Walk</td>
<td>Walk</td>
<td>“</td>
</tr>
<tr>
<td>6 – 10 months</td>
<td>Sit up</td>
<td>Sit up</td>
<td>“</td>
</tr>
<tr>
<td>2 – 4 months</td>
<td>Smile</td>
<td>Smile</td>
<td>“</td>
</tr>
<tr>
<td>1 – 3 months</td>
<td>Hold up head</td>
<td>Hold up head</td>
<td>“</td>
</tr>
</tbody>
</table>
I also wonder why the particular ‘abilities’ are selected. The idea of a twelve year old stage of development being defined as ‘holding a job’ seems only there because it allows a read across with person with mild dementia losing that capacity. It doesn’t seem an appropriate descriptor for most of the twelve year olds I know.

The same applies to the comparison of language development and decline. Although people with dementia do have progressive loss of language it seems far less systematic than this implies. We have all I’m sure observed moments of lucid communication in people in the last stage of dementia and the pattern of language disorder varies considerably depending on the cause of the dementia. Vascular dementia and frontal lobe dementia may affect the language centres of the brain in different ways.

Now I acknowledge that Reisberg’s table refers only to ‘Alzheimer’s disease’ but this again raises the question as to why one particular cause of dementia should parallel normal child development while others do not. Indeed the comparison of Alzheimer’s disease and normal human development in Reisberg’s table does not really seem to me to be a comparison of like to like. Alzheimer’s disease is surely not normal development even in reverse. It is not an inevitable loss of function that comes with age in the way that acquiring new skills is an inevitable part of growing up. These losses may be associated with dementia, as they are with other chronic neurological conditions, but they are not normal aspects of ageing. One in five people over the age of 85 may have dementia but that means that four in five do not. Dementia is not inevitable in people in their 80s, 90s or even over 100.

This person is 101.
Professor Tom Kirkwood (not to be confused with Kitwood) in his recent Reith lectures *The End of Age* argued that far from the frailties of old age being natural or inevitable they were the result of system failures. We are not genetically programmed to die, he says, our genes aim to live for ever and could do so if disease were eliminated.

Well, even if we find the theoretical basis for a second childhood flawed, does the concept help with good care as its supporters argue?

I have to say I find accounts of the use of functional scales by caregivers dispiriting. As far as I can tell by reading carer’s accounts on websites seeing dementia as an ordered decline encourages a rigid, authoritarian, deficit based approach to care. Caregivers anticipate and plan for the next failure, they concentrate on the loss of ability. They are indeed reinforced in all the ways of caring that Kitwood described as malignant; such as labelling, disempowerment, disparagement and infantilisation. Not surprisingly they describe their caring experience in negative terms as a constant battle against decline.

*The most particular manifestation of the second childhood is in what is called ‘doll therapy’.*
Someone To Care For - Pink

00495
BLUE EYES / BLONDE HAIR
A DONATION OF $2.50 FROM THE PURCHASE OF EACH DOLL IS BEING MADE TO THE ALZHEIMER'S ASSOCIATION

The realistic, soft cuddly body, floppy head, beautiful eyes and sculpted hands and feet of "Someone To Care For" is the perfect gift for someone special in every family. This excerpt from a My Own Baby owner is typical of the many letters we have received from friends and family members: "The smile on this doll's face has brought much joy to the owner. When she looks over at the doll, the biggest smile you've seen comes across her face. The doll isn't a doll anymore, it is now a child. She loves it as though it is real. The proud owner has Alzheimer's and is 89 years old."

Spinning Wheel Price: $99.00
This doll, according to the sales pitch, has ‘brought much joy to the owner. When she looks at the doll the biggest smile you’ve seen comes across her face. The doll isn’t a doll any more it is now a child. The proud owner has Alzheimer’s and is 89 years old’. The Alzheimer’s Association it appears will receive $2.50 for every doll sold.

I can understand why some people like dolls. Lots of adults do and many of us cling onto a much loved teddy bear or other soft toy long into adulthood. I have to say, seeing the impact of my two year old niece on a whole ward of people with severe dementia some years ago, that real children do the job better.
But real children can’t always be pressed into service.

So giving someone a doll if it makes them happy, less anxious, more occupied seems like a creative way of caring.

What I have more difficulty with is so-called ‘doll therapy’. Ilse Boas, a carer suggested in the Journal of Dementia Care Boas (1998) that a whole new range of ‘therapies’ are being invented to satisfy the needs of workers rather than people with dementia. It makes care workers feel important, she argued, to be providing ‘therapy’ but in fact the content is less important than ‘the human interaction, the companionship of fellow human beings’.

Doll therapy involves ‘therapy sessions’ in which dolls are introduced clients and to used to ‘stimulate memories of a rewarding life role, especially that of a parent’ and to act as a focus for reminiscence and conversation.

A review of the scant research on this approach by Jackie Lloyd and colleagues (2000) concludes,
• The mental deterioration that occurs through dementia often reverses the normal development of a child into an adult so people with dementia are often childlike in behaviour.

• The literature is biased – it reports doll therapy as positive without any flaws… it is not substantial enough to make decision as to whether or not to use doll therapy.

Jackie Lloyd et al, 2000
And why only dolls? Why not toy therapy? Do men respond to dolls the way women do? Perhaps we could have some ‘toy train therapy’ for men.

Maybe we already do.
I'm confused as to whether this 'doll therapy' is conscious play or deceit. Do we know this is a doll? Or are we pretending it is a baby? Are we colluding with a misunderstanding or are we asking people with dementia to collude with us? When children play make believe 'let's pretend' games they absolutely know it's pretend.

That is why it is safe and liberating. It enables us to try out roles, take risks, explore relationships.
One of the problems with the ‘childhood’ image is that it allows adults to take decisions on behalf of others and can be used to justify deceiving people ‘in their own interests’.

Recently in a public debate we have had in the UK about the ethics of giving people with dementia drugs without their knowledge or consent several of those who wrote to me approving the practice said it was justified because people with dementia ‘were like children’.

Ironically good practice in child care is moving increasingly towards reinforcing and supporting autonomy in children rather than making decisions on their behalf.

I do think, however, acknowledging the childlike qualities that sometime seem apparent in people with dementia can help us to understand and a respond to them effectively. I’d like to make some different comparisons from those made by Reisberg.
Consider for instance the temper tantrums of a three year old.

Is this comparable with the catastrophic reaction that a person with dementia may experience. As an uncontrolled response to frustrated will and powerlessness in the face of an incomprehensible world they both seem explicable. Temper tantrums in children can be understood on a number of levels but most simply as the painful response to discovering you are not the centre of the Universe and that you cannot always have your own way. As Christine Bryden of the Dementia Advocacy and Support Network has said for a person with dementia responding abnormally to an abnormal situation can be normal. We can interpret such expressions as bursts of existential rage against a world you cannot control.
Consider too the role of food and eating.

Children don’t have to learn to eat – they do that from the moment they reach the breast - but an immense amount of time is spent by them and their parents in playing with food, accepting, rejecting and giving food, and thereby socialising the process of eating. Food and eating, or not eating, are also important in the lives of people with dementia, using inappropriate implements, eating with your hands, pushing food out of your mouth, tasting odd things or eating strange combinations are all part of both childhood and dementia relations to food. Eating behaviour in infants is primarily an expression of will and of control over the environment.

I think we undervalue the importance of food and eating in dementia care. Having control over what you put into your mouth is an early autonomy we acquire and is almost the last we retain. Refusing to eat is a legitimate expression of self-determination. That is why feeding by tube is such an invasion of dignity and autonomy.
There is another sense in which accepting the childlike may help us care.

The stress on choice and freedom which rightly comes with person centred care may underestimate the need for safety and security. In a recent study of what quality meant to older people (Quereshi & Henwood 2000) feeling secure came high on their measures of well-being.

In a thoughtful study from Sweden, *Experiences Related to Home in people with Alzheimer’s disease* Karin Zingmark notes how many people with dementia in institutional care are preoccupied with talking about their parents and insist on going home. Leaving our childhood home is part of becoming an adult. Acknowledging the need for the feeling of home, of connectedness, of being safe and being cared for are all essential ingredients for the well-being of children and adults living in institutions.
Acknowledging the childlike in someone’s behaviour does not require us to infantilise the whole person.

Val Bradshaw, a carer, spoke at one of our support meetings the other week. One thing she said about her husband was; ‘I knew when he was frightened as he came and stood next to me and held my hand like a child’. But then she concluded ‘People with dementia are not stupid, or children, or deaf, and shouldn’t be treated as such’.

Barbara Pointon, a carer, describes her husband Malcolm, a musician and music lecturer as ‘bouncing up and down like a baby’ in time to the music. But his childlike pleasure does not lead her to conclude that he would prefer nursery rhymes to Mozart’s Don Giovanni.
Childhood is indeed a compelling metaphor for some of the vulnerabilities and losses of old age. But it is just a metaphor. A comparison which gives us insight. The sense of self and self-determination we have as adults is hard won through our childhood and adolescence. Let’s not take that away. We should aim to preserve it not undermine it.

People with dementia are not going backwards, they are not going round in circles. They are going forwards, on a journey many of us will have to go on but none of us want to make. They carry their childhood with them, as they do all the ages of their lives. We shall care best, and be cared for best, if we accept the child in all of us but never forget we have grown into adults.