



MASE Monthly Newsletter



Proud Recipients of Queen's Award for Voluntary Service

August 2019



It is unbelievable to think we are in the 8th month of 2019. Many Carers will now be thinking of taking a holiday and before we know it, everyone will be talking about the Festive Season!

For those of you who are going away, please take care and try to enjoy your break. Take the time to re-charge your batteries, and make the most of precious moments whilst you are away.

However, holidays can include many people, and this can sometimes cause confusion and anxiety for a person with Alzheimer's.

Remember to keep your routine as close to normal as possible.

During the hustle and bustle of the holiday be aware of fatigue and find time for adequate rest.

The Daily Mail's Six Demands to end Dementia Crisis

1. The new Prime Minister must urgently announce a plan to end 22 years of delay by setting up a cross-party group to tackle the social care funding crisis.
2. This immediate investigation must examine all options for funding dementia care - for example, via pension contributions, new tax breaks for social care spending, or an innovative care insurance scheme.
3. The creation of an NHS 'dementia fund' to help families pay the extra costs of looking after those affected.
4. An end to the 'double subsidy' where care homes charge a higher rate for private residents than they charge councils to look after patients who have no savings... despite both cases receiving identical care and facilities.
5. A dedicated Minister to attend Cabinet with sole responsibility for delivering on the dementia care crisis once and for all.
6. That no-one should be forced to sell their home to pay for their dementia care costs.

Quotes from

Jeremy Hughes: Alzheimer's Society: Social care is in a desperate state, in urgent need of a complete overhaul. Decades of underfunding have left people with dementia struggling with a system that is unfair and unsustainable.

Niall Dickson: NHS Confederation: The state of social care is a national disgrace and the next Prime Minister needs to make it a top priority.

The Daily Mail has really come down on the Dementia Care crisis and have exposed the scandalous injustice of dementia care costs. They are asking when will our political class end decades of neglect and actually **DO** something to help people who are on this journey.

For those of you who are conversant with emails - the Daily Mail is asking for details of any financial hardship you have undertaken because of the costs associated with dementia care. Their email address is dementiacare@dailymail.co.uk

The CD of the MASE 10th Anniversary

The CD of our 10th Anniversary Event in April is available for you to purchase as a memento of what was a truly fantastic afternoon. The CD's are on sale at £2.00; this helps us with costs we incurred in the making of the video of the Anniversary and transferring it then to the CD's. The CD completely captures the essence of what the MASE stands for; showing people laughing, dancing and having a wonderful afternoon together. No-one watching it would be aware of the difficult journeys you are all on.

Carers we salute you ALL for the wonderful work you do, for the love, care and commitment you show to your loved ones and for doing it all with a smile. You are all incredible.

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Alzheimer's Society Dementia Helpline 0300 222 1122 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

Looking after your cared for on their Dementia Journey

I do hope you will find this information helpful; you may too at the end of it shed a tear – because we **ALL** know how difficult the Alzheimer's journey is. Whether you're still on the journey, or have walked the pathway and now living without your loved one – this will touch your hearts ... of that I am sure.

This for those of you who may have a loved one who either has some form of dementia already, or you think is heading that way. There are some tips for you, it is definitely not an exhaustive list and words/phrases that have been used in the hope that you find something useful to get you through your day.

A different world

The best piece of advice is, "Move into your loved-one's world". Keeping your loved one content and safe is a priority and the best way to do that would be to imagine the world they are in:

Don't contradict - if they say "I don't live here" learn to say, "I know, but it's nice for a visit and it's very posh, don't you think"?

Don't give sad news - particularly a bereavement. Probably best to not say anything at all. To the person with dementia it would be like going through the same bereavement over and over again. Can you imagine that heartache?

Many things can be learnt by talking to carers and other professionals as well as reading and observing. It may not work for everyone but can be a revelation for many people.

Dignity - since no-one has ever come back from dementia to explain what it was like, work on the basis that whatever your loved one likes and dislikes, and what their standards were pre-dementia, then try hard to keep to that. When the time comes to deal with incontinence for the first time try to understand. The situation will arise many times going forward, try to change pads with little fuss and great dignity and respect. And one of the few up sides of this vile disease is that your loved one will never realise what is happening to them.

Selfcare – Your family and close friends are important to you; true friends will go above and beyond the call of duty on many occasions.

Be kind to yourself. If you don't get respite you won't be able to 'care' properly. If people offer help, take it. If you need help, ask for it. Take a break as often as you can - you'll never fully relax but you'll re-charge your batteries. There will be a few people who will surprise you and some who will let you down. Some sound advice is to move away and concentrate on the steadfast, reliable and trustworthy ones. You know who they are already.

Practical things:

Make the surroundings familiar with photos, perfume, cushions, music that your loved one likes.

As eye sight weakens use red crockery which is seen easier and replace knife and fork with a spoon.

Keep the TV on an appropriate channel.

Cover or remove mirrors. To the person with dementia their own reflection is like a stranger in the room. Imagine how frightening this must be.

Always say who you are each time you walk back into the room. Because even though you want to believe you are recognised you can never be sure.

Make sure you use lots of facial expressions, touching hands, kneeling down to speak at eye level, in a gentle voice.

Appreciate every stage – This is so hard to explain, here are some examples.

When someone repeats the same phrases dozens of times in half-an-hour it is difficult. However, when you lose someone, or as the disease progresses, you would give anything just to hear the sound of their voice again.

When they misjudge eating or have spilt something; think that at least they can still use their hands and arms, and they are actually still eating .

The point is this, whatever you're annoyed by or upset about there will come a time, further on, when you'll wish you could go back to that time. Accept what stage you're at and always look for the positives.

Always assume your loved one knows who you are, can hear and understand what you are talking to them about and can sense how much they are loved.

Conclusion

At the heart of everything you do, be patient, kind and caring – like you would look after an infant really.

When the time comes and your journey is over, remember you have done your very best as this dreadful disease has taken its course. Look back when you are strong enough and always remember you did everything you could to make your cared for feel secure and loved.

If you have a computer please take a look at our website which covers all MASE activities: www.themasegroup.com

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