

RESPITE 2 & 4

It's easy enough to allow that carers are chosen for their vocation and the reason they're put in this position is because they possess three necessary attributes. These being a practically applicable compassion gently tempered with an inexhaustible font of love and a simple all encompassing patience. But right from the start and to do this subject of carers respite justice we first have to acknowledge the fact that carers need effective respite as much as those they care for need carers.

And for those of us who have been blessed with the possession of those three stand alone components we need to properly recognize the essential role carers play in the continuing well-being of those special people that we care for.

But this essay is meant to be about delivering respite for carers rather than it being about cares or respite as an indivisible entity. Paradoxically we can't begin to talk about the topic of carers respite until we define those two crucial words "carer" and "respite" separately.

To begin with the accepted definition of a carer is that of an unpaid family member or friend who provides significant levels of care and support to an adult or child who has a disability, a mental illness, a chronic health condition or who is frail aged.

All carers toil at the same coal face of special care provision for special people under special circumstances. Day in and day out week in and week out the carers situation usually lapses gently and barely noticed into days past without a hint of complaint or dissent. All of this because of compassion, love and patience properly delivered to the ones carers care for. That plus a sense of duty born of the functional love of one for the other.

Given their preferences a list of the I wants for these same carers might typically include social support activities such as a carers days off, carer retreats, education courses (including carer awareness courses), information evenings and guest speakers as well as specified support groups including, monthly issue-based and social support groups where carers can enjoy at least some small respite from their non-stop role of carer.

At the same time there are degrees of disability therefore there are degrees of dependence but the one unarguable constant is that there exists a constant and continuing need for respite for the carers but there can be no degrees of respite.

Regardless of the required degree of care any carers normal day might be as basic as doing all those mundane chores that won't go away by themselves and that every care provider has to coordinate in order to maintain and make a house a home.

However, having said that, once we factor in the enormous amount of time and effort in providing full time care for a person with special needs is it any wonder that carers require some respite? Especially when there is nothing on the carers radar to suggest that things will improve with time because in too many instances they won't and it's

actually more than likely that any given situational example can only deteriorate into an unmanageable system-wide carer-specific melt-down.

So we can ask here what do we know about carers? Well, we actually know quite a lot. We know that 71% of primary carers are female. 79% of primary carers care for a person in the same household. Care is mostly for a partner (43%), child (22%) or parent (24%). Most primary carers are of workforce age (75% are aged between 15 and 64 years). Even though the majority of primary carers are of workforce age, paid work is usually not possible. 52% are not attached to the workforce. 47% of primary carers receive a government pension, benefit or allowance. 40% of primary carers have been providing care for a decade or more, and 68% for more than 5 years. Most primary carers (57.4%) said that they provided care because it is a family responsibility; 40% believed no one else was willing or available; 20% found alternative care too costly.

We also know that many carers are among the poorest, most disadvantaged people in our community. About 45% of primary carers in 2003 reported incomes that place them in the lowest and second lowest gross household "quintiles". While incomes may be low, the costs of caring such as medical and pharmaceutical expenses, consumables, aids, equipment and support services can be significant.

Which brings us to the word respite. So we can ask here what do we know about respite? Well we actually know quite a lot.

A definition of respite includes a delay for a time of anything distressing or an interval of relief or to relieve temporarily or give an interval of relief from.

Included here are a few especially relevant synonyms and there must be at least one word somewhere that every carer can connect with. Words and phrases like: breathing space, deferment, downtime, freeze, halt, hiatus, intermission, interval, layoff, leisure, let-up, lull, recess, release, relief, reprieve, respite, rest and time out, will be decidedly popular in the carers community.

On the subject of respite for carers the ever present difficulty is that oftentimes those most in need by having voluntarily assumed the position of primary carer for someone with special needs refuse to take a well earned respite for themselves. This because of various but easily recognized and not unsubstantial reasons.

Just a few of the many reasons for a carer not taking advantage of any respite include that the carer will nearly always put their own welfare last. It might be that the carer has no knowledge of the relevant agencies who might be able to assist in the planning and execution of some respite or the sometimes all-inclusive task of organizing any respite is simply not worth the effort and that nobody else can do the job as well as them.

Despite this and all things being equal, these carers, in their wonderfully understated way, would happily settle for respite care every so often and a days respite here or there has been shown to be marvelously therapeutic for all concerned parties. But while entirely desirable the practicalities of respite care are such that there will always be a veritable barrage of artificial barriers to overcome before respite care can even begin to be organized and then hopefully put into place.

Having advanced to the position where we are able to acknowledge and therefore recognize the everyday needs and wants of the carers in our community we can now begin the discussion on the specifics of “carers respite”. Which of course includes not only what respite carers need but also the more complicated situation of what respite carers want.

For those with access to the internet there is a plethora of relevant websites available on the subject of carers respite but an excellent place to begin any search is the Carers Victoria website. Simply key “carers vic” into your browser and you’ll open a whole new world that supplies the many answers to the many questions most frequently asked for and about carers respite.

As things often work out the task of being a real-life real-time carer brings with it at least some small appreciation of the carers prodigious workload. On special occasions, when that appreciation is verbalized, or the occasion generates a thank you smile from the one you care for it brings with it a sense of well being to the carers and provides the wherewithal for them to continue to confront the dark unknowns that belong to a partly predictable and partly uncertain tomorrow. Ironically this unlooked for appreciation of a carers input is in itself a form of respite.

And it follows that a whole of life commitment, such as being a full time carer, doesn’t just ask for the compassion and love and patience – it demands it. But in the end of it all that’s just what carers do. We care. With or without respite carers continue to care for our special charges in a special way under special circumstances with special unlooked for rewards.

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CARERS CARE.....(That's what they do!!)

Given different circumstances no one would choose to become a carer of someone with special needs. The reality of the situation is actually the opposite. I've reason to believe that carers are especially chosen for their life's vocation and that we're chosen for those three necessary attributes that we all of us possess if we care enough to seek them out. These attributes are a practically applicable compassion gently tempered with an inexhaustible font of love and a simple all encompassing patience.

My heart goes out to those carers of people with special needs. I've wept the futile tears of despair both for you and with you. And given a set of unfortunate circumstances it must be unimaginably burdensome to be in your twilight years and still looking after a son or daughter at home. Inevitably one is forced to reconsider the continuing well being of the entirely blameless charge when the carer no longer possesses the wherewithal or capacity to look after them. And that question takes on a stridency or an urgency all of its own with the inevitable passage of time.

But as in all things in life there are degrees of cause and effect that need to be carefully calculated. There are those with special needs, one so different from the other as to be effectively opposites. There are degrees of required care for each charge that are so varied as to be effectively opposites. And there are degrees of reciprocal inter-action between carer and charge that are effectively opposites. Ensuring just such a balance and a best position scenario is one of the major roles of a carer.

In my travels in the wasteland that is mental illness I've met carers who've been looking after their charges for twenty years and even more. They are truly the unsung heroes in our community. Those of you who've not been imposed upon should try to imagine never having a day or night off let alone any proper sort of holiday. You'll likely find this thought experiment impossible to replicate because the undriven devotion to duty necessary for these carers to do what they do is as far removed from the realms of normalcy as is the usually inaccurate public perception of an unaffected entire body and entire mind experience. But that is a whole different chapter in a whole different book.

Reciprocated love is what we mostly get for our efforts in providing full time care and in and of itself this intersection of freely given and freely accepted love can be thanks enough for your input. God knows it's not the attraction of payment for work undertaken. And by looking after my special needs friend at home I'm saving the government an enormous amount of money once you factor into the equation the undeniably prohibitive cost of modern specialist accommodation.

A whole of life commitment, such as being a full time carer, doesn't just ask for the all too uncommon trilogy of compassion and love and patience – it demands it. But in the end of it all that's just what carers do. They care for their special charges in a special way under special circumstances with spectacularly special unlooked for rewards.