

19 JUNE 2008.

SECRETARY
INQUIRY INTO BETTER SUPPORT FOR CARERS
STANDING COMMITTEE ON FAMILY, COMMUNITY,
HOUSING & YOUTH.
PO BOX 6021
HOUSE OF REPRESENTATIVES
PARLIAMENT HOUSE
CANBERRA ACT 2600.

Dear Secretary,

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing & Youth's Inquiry into Better Support for Carers.

Unfortunately, my computer is broken, & my financial position does not allow for repairs or replacement at this stage. Consequently this will have to be handwritten. It seems that with no computer access I have lost contact with most services in today's technological age.

I will do my best to outline important issues in a way which I hope will be easy to read and understand.

1. MY ROLE AS A CARER IS EXHAUSTING, FRUSTRATING, TIME-CONSUMING AND NOT ALWAYS REWARDING. I CARE FOR A TERMINALLY ILL MAN WHO SUFFERS FROM DIOXIN POISONING (NOT ACQUIRED DURING MILITARY SERVICE), POST-POLIO SYNDROME, PLUS SKIN AND NERVE DAMAGE. HE IS 62 YEARS OLD, BUT UNABLE TO FUNCTION IN MORE THAN BASIC WAYS.

I TAKE CARE OF EVERYTHING. AS WELL AS HIS CARE THIS INCLUDES CLEANING, SHOPPING, COOKING, HOME MAINTENANCE, DRIVING HIM TO MEDICAL APPOINTMENTS, TAKING CARE OF FINANCES. IT IS DIFFICULT TO BALANCE THIS WITH TIME FOR MYSELF.

MY ROLE APPEARS TO DEFINE ME NOW. THERE IS NO RECOGNITION OF THE PERSON I WAS - WHO WORKED FOR MANY YEARS IN SOCIAL WORK, DEVELOPING MANY COMMUNITY AND SOCIAL JUSTICE PROGRAMS WITH HUGE BUDGETS; A MUSICIAN AND CREATIVE PERSON, A WRITER, A MOTHER AND GRANDMOTHER.

2. I CONTRIBUTE TO SOCIETY BY PROVIDING A VERY COST EFFECTIVE SERVICE AT HOME. I AM AVAILABLE 24/7. IF I WERE UNABLE TO PROVIDE THIS CARE, INSTITUTIONAL CARE WOULD BE THE ONLY OPTION AS HE WOULD NOT CARE FOR HIMSELF IF LEFT ALONE.

1. BELIEVE THIS CONTRIBUTION SHOULD BE RECOGNISED BY:

- MORE FINANCIAL ASSISTANCE.
I AM UNABLE TO WORK.
BILLS ARE CONTINUALLY INCREASING
BUT MY INCOME DOES NOT.
I AM IN RECEIPT OF AN AGE PENSION
(I AM 64) PLUS CARERS ALLOWANCE.
- EASIER ACCESS TO REGULAR BREAKS
- EASING OF CRITERIA FOR ASSISTANCE.
NOT EVERYONE FITS THE "ACCESS
CODES" AND CAN MISS OUT ON HELP.

2. MY CARING ROLE AFFECTS MY LIFE

BY:-

- HAVING 24 HOUR RESPONSIBILITY IS VERY LIMITING. IF HE WERE IN INSTITUTIONAL CARE FACILITIES SUCH AS LAUNDRY, MEALS, CLEANING, TRANSPORT ETC. ARE PROVIDED. CARERS CAN LEAVE AT THE END OF THEIR SHIFT. I DON'T HAVE THAT LUXURY!
- I HAVE NO SOCIAL LIFE ANY MORE
- I ALMOST NEVER SEE MY FAMILY.

3. I FIND IT DIFFICULT FINANCIALLY BECAUSE:-

- \$320 PER WEEK TO PAY FOR EVERYTHING IS A STRUGGLE.
- I AM STILL PAYING A MORTGAGE.
- FUEL, FOOD, ALL BILLS CONSTANTLY INCREASE.
- HAVE TO CUT DOWN WHERE I CAN.

- FOR EXAMPLE, NO SOCIAL LIFE.
- NO UNNECESSARY CAR TRIPS.
 - UNABLE TO REPLACE MY 18 YR OLD STOVE WHICH IS NOT WORKING PROPERLY.
 - MY COMPUTER IS NOT WORKING WHICH DENIES ME ACCESS TO MANY SERVICES AS WELL AS THE ABILITY TO WRITE, EMAIL FRIENDS AND FAMILY.
 - HAVE TO SOURCE CHEAP FOOD WHEN I CAN.

4. THE BARRIERS I EXPERIENCE IN FINDING OR RETAINING EMPLOYMENT! -

- MY AGE IS AGAINST ME!
- I COULD NOT COPE WITH BOTH CARE AND EMPLOYMENT RESPONSIBILITIES I RARELY HAVE A FULL NIGHT'S SLEEP, AND NEVER KNOW HOW HE WILL BE FROM DAY TO DAY.
- WHO WOULD CARE FOR HIM IF I WERE AT WORK?
(DON'T EVEN THINK OF TRYING TO GET ME BACK TO WORK!)

5. THE PRACTICAL MEASURES WHICH WOULD BETTER SUPPORT ME INCLUDE:

- MORE FINANCIAL ASSISTANCE!
(JUST OVER 30¢ PER HOUR FOR WHAT I DO IS AN INSULT, AND YET WITHOUT IT I WOULD NOT MANAGE)

← HELP WITH LAUNDRY. HIS SKIN CONDITION MEANS HE BLEEDS A LOT AND I AM CONSTANTLY CHANGING AND WASHING BEDDING AND CLOTHING.

- AFFORDABLE TRANSPORT. THE CARERS ALLOWANCE OF \$50 PER WEEK DOES NOT COVER CAR RUNNING COSTS, ESPECIALLY IF NEEDING TO TRAVEL LONG DISTANCES TO MEDICAL APPOINTMENTS ETC.

- RESPIRE SHOULD BE EASIER TO ACCESS.

- HE HAS BEEN REFUSED AN A.C.A.T ASSESSMENT AS HE IS "TOO YOUNG."

- I HAVE BEEN TRYING FOR NEARLY 3 YEARS TO FIND A WAY TO PLAN FOR THE FUTURE AND ACCESS TO REGULAR BREAKS. IT SEEMS I MUST WAIT FOR AN EMERGENCY SITUATION TO DEVELOP.

- SEEMS TO BE IMPOSSIBLE FOR HIM TO GO TO RESPIRE, AS HE IS ALCOHOL DEPENDENT. HE IS NOT AGGRESSIVE BUT SIMPLY FALLS ASLEEP. THE REASON FOR DENYING HIM ACCESS WAS "WE CAN'T PUT STAFF AT RISK." FAIR ENOUGH. BUT WHY IS IT OK FOR ME TO BE AT RISK 24/7??

ACCESS TO "TIME OUT" FOR CARERS.

RECENTLY I WAS FEELING RUN DOWN, TRAPPED AND DESPERATE FOR SOME TIME ALONE, TO RECHARGE AND REMEMBER WHO I AM - I WAS AN EMPTY SHELL, NO-ONE WOULD TAKE HIM.

I WAS FINALLY ABLE TO ACCESS 3 DAYS AT A RETREAT ^{FOR MYSELF} FUNDED BY RESPITE CARE, WHO ALSO PROVIDED DAILY IN-HOME CARE FOR HIM. THIS TOOK MANY PHONE CALLS AND 2 WEEKS TO BECOME A REALITY. TO ACHIEVE THIS I HAD TO ADOPT A "TERRIER" MENTALITY AT A TIME WHEN I WAS AT MY LOWEST. THE BREAK WAS WONDERFUL; WOULD IT NOT BE BETTER FOR ME TO BE ABLE TO ACCESS THIS ON A PLANNED AND REGULAR BASIS? THIS COULD PREVENT SITUATIONS WHERE A REAL EMERGENCY MAY OCCUR.

A CREATIVE APPROACH COULD BE

- TO ASSIST ME TO HAVE AN OVERNIGHT STAY IN BRISBANE, PERHAPS, TO DO SOME THING I MIGHT ENJOY.
- ASSIST ME TO VISIT MY FAMILY INTER STATE OCCASIONALLY. THERE IS NO-ONE IN QUEENSLAND FOR ME.

- IT WOULD BE GREAT IF CONSIDERATION COULD BE GIVEN TO HELP FUND ALTERNATIVE THERAPIES (MASSAGE, HOMEOPATHIC REMEDIES, HERBAL TREATMENTS, ACUPUNCTURE.)

STANDARD MEDICAL TREATMENTS DO NOTHING FOR THE PERSON I CARE FOR. THE ALTERNATIVE TREATMENTS MENTIONED HAVE BEEN OF IMMENSE BENEFIT BUT ARE EXPENSIVE AND SO NOT EASILY ACCESSED FOR A PERSON LIVING BELOW THE POVERTY LINE.

FINALLY, A PRACTICAL SUGGESTION WOULD BE A CASE MANAGEMENT APPROACH. WHEN CARE BECOMES NECESSARY, AN INTAKE AND ASSESSMENT FACILITY, LOCALLY, WOULD ASSIST CARERS TO FIND THEIR WAY THROUGH THE MAZE OF CRITERIA, SERVICES, PAPERWORK ETC. I HAD BEEN A CARER FOR 3 YEARS BEFORE I HAD MY 3-DAY BREAK. I'M WONDERING WHY I WAS NOT INFORMED OF THE POSSIBILITY BEFORE THEN?

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing the recommendations you make in order to improve support for carers. I am also happy to be contacted at any time to discuss ideas + how they may affect this dedicated group of people.

Yours sincerely,

PAT