

## THE BURDEN OF CARE

## EDITORIAL

For Christians, the title "Burden of Care" may seem odd. Care for others is surely a Christian duty and Jesus promised that those who cared for the prisoner, the disadvantaged and those in need would be blessed – they are doing His work. Several of the articles reflect this, telling of joy in caring, of managing to cope with numerous additional family members orphaned through AIDS, of parents coping with a disabled child, of children coping with younger siblings. In countries such as Papua New Guinea and many parts of Africa, the extended family and local community frequently help to

shoulder care burdens. But even here, the spread of urbanisation is weakening this culture of extended family and village support. Throughout the Anglican Communion, more help is needed for families as the ravages of AIDS creates an ever-increasing number of orphans, as more handicapped children survive, as more people grow older. While the family, and particularly women, remain a primary focus of care giving, the culture of care needs to spread more widely into the surrounding community – in cities as well as rural areas. The Church, an inter-generational community with a culture of care, is ideally placed. Many of the articles tell of projects linked with churches which work to help those in need of care and their families and of people who gain

fulfilment in so doing: Kingsdene special school in Australia, Salvation Army work in Zambia, Mothers' Union work in Rwanda, projects to help young carers in the UK. Some of the articles from Africa rightly remind us of the importance of prayer. But these projects also need resources and hard work to help shoulder the burden of care and obey the command of Our Lord to serve those who are afflicted.

Reading of the courage and cheerfulness shown by families and individuals bearing seemingly impossible burdens is both humbling and an inspiration. Perhaps it will help us all reflect on what some people do for others and encourage us in our own Christian pilgrimage.

## SOUTH AFRICA

A young lady knelt in front of me to be confirmed. After confirming her she asked me to bless her baby. Then she told me that they both had AIDS. They were people with beautiful faces and who were afraid, lonely and dying. Six months later I am told that both have died. Within the geographical boundaries of my Diocese, the AIDS pandemic is affecting every community. In a rural parish a mass funeral is held for those who have died recently, mostly of AIDS. The burden of care is considerable for all concerned.

The title "Burden of Care" should be a contradiction in terms, for care should be a privilege, a responsibility and even a joy. 'Burden' conjures up a picture of a beast of burden, heavily weighed down almost to the point of collapse. Care is something that should spring from us out of the sheer milk of human kindness, if not Christian conviction. Within this area of the Diocese of the Highveld, as in many other parts of Africa, we often feel that the sheer weight of need around us is overwhelming. It feels like a burden. The AIDS pandemic has the potential to decimate a whole generation and in parts of the Diocese it is estimated that up to

50% of the population may now be infected with AIDS. The demand for home-based care schemes, homes for AIDS orphans and educational assistance for those whose parents have died of AIDS is continually increasing and is placing huge burdens on every community. We are told that half of those who at present are 18, will be dead by the year 2005. The Diocesan AIDS Co-ordinator believes that that is a modest estimate. A young person was asked recently what they wanted to be when they were 21 years of age. "Alive" was the reply.

Within the Diocese AIDS is not the only issue of concern. There is a high rate of unemployment. Just half an hour from the centre of Johannesburg, which is the commercial capital of South Africa, the rate of unemployment is around 38%, a rate that continues to climb as one moves into the rural areas of the Diocese. Then there are huge needs on the educational front at every level from pre-school to primary school, secondary school and tertiary education. In the rural communities, young children walk long distances every day to attend classes.

"Are there then no hopeful signs?" you may well ask. When facing the need for care, one needs to view it from a micro and not from a macro perspective. When we look at the overall problems it is easy to be bowed down. What can we possibly do that would make any difference? But it is a case of reaching out to those near at hand and doing what one can for them, knowing that for a few at any rate, their suffering may be relieved. The reality is that everyone can make a difference to the life of someone close by who is in need. It is also a question of education by making the problems known to those in a position to give financial and material help, as well as loving care.

Jesus tell us: "Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me". Yes, the burden of care is for us considerable. But we do it to bring hope, comfort and joy to those in our midst and as part of our call to be disciples of Jesus.

## MALAWI

### The impact of AIDS

Exact statistics for Malawi are hard to come by, but it is believed that out of a population of between 10 and 11 million people there are now at least  $\frac{3}{4}$  million orphans under the age of 16. In Zomba district over 20,000 such orphans are registered, and in each sizeable village orphans are usually numbered in their 100s rather than in 10s. A few orphanages exist in the main centres, but it is generally the extended families, or by default the village communities, which care for these children.

At our theological college almost all married students have responsibility for other children apart from their own. Indeed, a rule has been introduced limiting the number of these orphans on campus to two per household. When single students get married they will certainly not begin their marriages in childless fashion, as almost immediately they will be expected to take charge of parentless nephews and nieces. Staff members too report a steady increase in the number of their charges; for example, one lecturer lost three sisters-in-law in the year 2001, each of them leaving six or

seven children in need of care.

There is thus enormous pressure on waged families to shoulder extra burdens. But these households are a

minority, and in fact it is more often the older generation who end up caring for their grandchildren. In the Songani Community Care Project covering several villages near Zomba, 410 orphans are registered and as the name implies they are looked after locally. It is clear that, although some of the guardians are a little younger, many are elderly grandmothers whose resources scarcely stretch to feed extra mouths and clothe extra bodies.

Not all orphans are as fortunate as these and there are children begging on the streets of the main towns and cities. Efforts by Non-Governmental Organisations to provide for them and to give them schooling have generally been unsuccessful, as the rewards of begging have a more immediate appeal. But those who are beggars today will be criminals and drug pushers tomorrow, and the fabric of Malawian society will then be tested even further.

## UGANDA

I married Eric in December 1972. He was working in an oil company and I was a High School Teacher. We had planned to have four children. By 1978, God had blessed us with two girls and two boys. In 1984 God added on another son. We were happy and contented and hoped to raise our five children within our resources.

Between 1986 and 1992 we had to take in and bring up eight more orphaned children from friends and relatives as a result of HIV/AIDS. Though the parents had died of AIDS, these children were all negative and growing up. We had to take care of these thirteen children without any external help. We had to sell off all the assets we had in order to pay school fees. The textile business I was doing

collapsed half way. We even had to sell off our nice five-bedroomed house and we are now living in a smaller unfinished house, without water, in a village. At one time, we had to pay tuition fees for three University students. We did all this because we had great faith in God. We count it a joy because we believed in Him, depended on Him, confided in Him, relied on Him and obeyed His word. (Romans 12: 12-13).

It is a challenge to live a sacrificial life. We were also faced with a burden of taking care of sick relatives and being responsible for their burials after death.

I am glad to say that out of the thirteen children, seven are out of University and are now working, with three of the girls now married. We are still struggling with the remaining six children but we believe that God will see us through. He is more than able. We are happy that these orphans are not street children but are useful citizens.

We still count it a joy.

## ZAMBIA

### **Bear one another's burdens.**

(Galatians 6: 2)

My eyes quickly went through the list of names that were forwarded to me by our sister church situated near Lusaka and rested on Mrs Mwansa (not her real name), estimated age 58 years with sixteen children to take care of. These children range from three to fifteen years; two of them are hers but the rest are grandchildren whose parents are both dead. Her husband ran away from home because of the difficulties to feed and care for this large family. She has no source of income at all.

The League of Mercy (a group of men and women that take care of social issues in Salvation Army congregations) from my congregation, together with the Lions Club, were going to distribute maize meal and other food stuffs to the vulnerable families and part of the criteria used to choose households is one that has taken in more than two orphans.

As soon as we got there I was on the look-out for this lady. "There she is" said our host Captain. She looked much older than her estimated age, a toddler clung to her skirt and a girl of about 10 years

whispered something in her ear which made her laugh. "What a woman," I thought to myself, "It was something for me to take care of eight kids for one school holiday; now this was sixteen not for a month but for the whole time!" "God bless you mama for the work that you are doing," I said to her stretching out my hand for a handshake.

She grabbed my hand with both of hers saying, "Thank you, thank you very much for this help, please come again. Love my grandchildren very much, BUT Pastor I have problems, big problems – to feed, and how do I send all of these children to school? My husband could not stand it so he left us to suffer. Life has many strange turns," she said and looked away from me probably to hide a tear.

Yes life has strange turns, I thought of the Shamambos fondly known as Mr and Mrs Honey – a lovely Christian couple full of laughter. Both are retired and have five grown-up children. The "baby" of the family, Naomi, just completed her first degree in Microbiology at the University of Zambia.

"My parents have always been very accommodating with other people so our

house was always full" recalls Naomi. "I was happy to have a room to myself after every one else left home and I got used to being just the three of us – me, my Mum and Dad. I did not have to look over my shoulder, as I was the last-born."

Then the strange turn came. Naomi went home for holidays and things had changed. "Where is my bed?" she asked when she got into the bedroom.

For there was now a new family of six. In November 1999, Mrs Honey's brother died. His wife died in 1997. They had a young family of five. One girl and four boys, plus one dependant whom these children felt was just one of them. "As a family we sat to look at the plight of my late brother's children and the natural thing for us to do was to split the children among the remaining brothers and sisters," recalls Mrs Honey. But the children had already discussed this among themselves and pleaded with the relatives not to split them up. The family then sat to look at it from the children's angle.

The family at large reasoned that the Shamambos were Christians, experienced parents, were loving though firm and had the space, since all their children were

grown up. These children were already having serious teenage problems so it would be difficult for another family member to handle them. The Honeys pointed out that they were both retired and without a very reliable regular income. The rest of the family said they would help every now and then. They accepted to try.

"It turned our plans, emotions and existence upside down," says Mr Honey. The oldest boy had just completed Grade 12 at the time of his father's death, his results were very poor. Next came the girl who was a Grade 9 and who decided to get married there and then. (This situation may be due to the fact that these two are the ones who nursed their mother and father.) The others were at different stages in school, with two not yet in school.

"I found life strenuous – you know that deep sleep is synonymous with old age. I would wake up in the morning and find that the children were already gone to school without breakfast!" says Mrs Honey. She eventually found a new way of preparing breakfast in advance. She now has to check schoolbooks and help with homework. All the children are doing fine in their schoolwork. The first one has completed training in auto mechanics with good results. The youngest is now doing Grade 3.

There are times when things are hard, there are moments when Mrs Shamambo wishes that her brother were there, but she says; "God has opened many channels to help, we have made it by God's Grace. Family members do help but these are hard times for all. The church also helps to meet the school fees for the children."

A word on Mr Honey? He loves, guides and encourages them: such devotion can only come from God. And Naomi? She has to look over her shoulder now but her special place will always be there in her parents' hearts.

"Help carry one another's burdens" (Galatians 6:2). To care by word of mouth and feeling, as James says "Go, I wish you well, keep warm and well fed," but does nothing about the physical need – what good is it?

It is not a burden to carry out this kind of care, but to fend for 16 children, when you are illiterate, unemployed and without a social scheme, to start a new family of six after your menopause and retirement – can you imagine? Caring is not a burden but to find the means, to clothe, educate, feed and meet medical bills in a country like ours, is a burden, which is managed by the grace of God.



The implementation of the Structural Adjustment Programme (SAP) has seen most of Zambian industries privatised, which has resulted in many people losing employment, in turn a lot of divorces. Due to lack of education, our women in most cases cannot cope with the new challenges brought about by such redundancies. The lower status of our women in Zambia is rooted in economic inequalities and discrimination in regard to equal opportunities in decision-making, as well as in society's reluctance to change attitudes towards gender issues.

HIV/AIDS is the second factor which is further aggravating the plight of women. Families are losing spouses who were bread-winners and our women are left to fend for their families. Also the rise in the number of children left as orphans is putting a lot of pressure on our illiterate women. The pace at which the most productive age group of the human resources is being wiped out through this pandemic is very high, and our women-folk really are the ones shouldering these burdens.

As a result of these constraints, our women's roles are changing very much. Women now are sometimes bread-winners of families. They are the ones taking the responsibilities of educating their children, using the resources available. Furthermore, women now also play a major role in ensuring that their families are provided with health remedies. So we can see that our women folk are embracing a lot of roles in their families, but sadly they lack the much-needed knowledge and skills to cope with these unveiling predicaments.

As a Church we would like to provide literacy programmes among women in the rural areas which fall under our operations. We would appreciate any support so that, as we grow as a new Diocese, we also put in place such programmes to empower our women with the much-needed skills for their vital burden of care.



# TANZANIA

## **Hisani Project – Centre for Women and Children's Rights**

This is a Non-Governmental Organisation, with the name of Hisani – a Swahili word which implies kindness. Our NGO was established in 1998 and registered in 2000. It is the centre for women's and children's rights; we support the rights for both of them in all ways which are required with all humans. We have a link with several churches, including an Anglican one, in the Mwanza region.

The children whom we support are those found in prisons. Bear in mind that they are not there because of their faults, but because of their mothers' mistakes, some being jailed while pregnant or having babies suckling on them. In the prison there is no clothing or special food for babies.

Due to the above problems, we decided to collect children from different prisons in the Mwanza Region, and put them together in our centre at Butimba prison because it was easier to provide them with essential services such as food, clothes, shelter and education.

For the time being we have almost 80 children in our centre. 70 are schooling in our kindergarten, while the rest are too young to attend.

We now have three centres, two in the Mwanza region and one in Mara Region. The number of children in each centre increases daily due to disease, increase of conflicts within the family leading to the separation of family members, and children moving to town and becoming the street children.

At first, the work of collecting them was very difficult, but as time went on it became easier simply because we made contacts between us and the chairpersons of different streets and villages. After communicating with these chairpersons, we found that in different families within the community there were children who were either orphaned or disabled. The use of different chemicals in the case of women, or being treated with rays, sometimes leads them to give birth to children who are disabled; others have accidents when young.

Most of such children are neglected by society, although they are innocent. We also distributed brochures which showed how to contact us. Sometimes we collected all members of the community in a meeting in which we educated them about what are the rights for children, no matter how they look or where they came from.

Due to lack of education, many lack the

foundation for their future life, and nobody is ready to take any action against this situation. Women are the family-makers, in co-operation with their husbands, but nobody is ready to listen to their cries. After we realised all this, we decided to conduct different meetings in which we educated them about their rights and how to support them.

Sometimes women, after the death of their husbands, are left with nothing to support their life and their children. Due to all this, we decided to provide loans to raise their income and help them support their lives.

Our aim is to make sure that the whole society is responsible for what is going on in the case of women's and children's rights. Also to recognise that even though these people are women and children, their rights should be supported effectively like any human in this world, no matter which community they came from.

## ETHIOPIA

### Children in Prison

In February 2002 Reverend Bob Spratt – formerly senior chaplain of Preston Prison – and I, travelled to Ethiopia and visited a number of prisons there. Pastor Daniel G/Selassie, Director of Prison Fellowship Ethiopia, who was our host, covers the whole of Ethiopia doing what he can to offer humanitarian aid and preaching the gospel. To do this he relies on volunteers from all denominations. Bob first visited in 1999 and has set up the Friends of Prison Fellowship Ethiopia to support the work going on there.

Ethiopia is a beautiful country but is recognised as one of the poorest in the world. Indeed there is so much poverty and resources are so limited, that prisons, almost inevitably, are near to the bottom of the pile – the poorest of the poor.

However, what I saw, even though I had been prepared, came as a shock. Two to three hundred people sleep in a shed the size of a small Church Hall. Sanitation and medical care is virtually non-existent – although a dedicated team of volunteer Christian doctors do now visit the prisons and offer what help they can.

A number of children, whose mothers are serving a sentence, are also living in these conditions because either they have nobody else or their families cannot afford to look after them. The food is lacking in nutrition and they receive no stimulating activities or education and in many cases their clothing was little more than rags.

At one prison Bob and I gave the children tennis balls and it became obvious that

they did not know what to do with them. Although you have to recognise that toys and playing are not part of the culture, we still found this very sad. We are trying to raise money for Parent and Child Units and to set up child sponsorship to pay for nutritional food, clothing and education. A lot of this will come from Christian volunteers in Ethiopia living out the parable of the widow's mite.



## RWANDA

### Child-headed households

The burden of care involves me as a Pastor, and my mind goes straight to the child-headed families around my local church as a result of the genocide and the war of 1994. One of these families is headed by a 19-year-old girl called Jeane, who cares for her two sisters and a brother. Her father died in the war of 1994 in a refugee camp and their mother, who had filled the gap of their father for almost six years, died in the year 2000.

The death of their mother made a total

change to the life of the children because they all wanted to go to school, and this contributed to the hard work and the burden of care of the older sister, who also goes to school in the morning and comes back in the evening to care for her little sisters and brother, looking for their food and other things for their well-being.

The burden of care remains a problem in our country due to the outcomes of the 1994 genocide – where the whole society is overwhelmed with the burden of care where possible and impossible. Jeane has

done a lot of caring for her family through difficulties, but the challenge is that she does it with a smiling face. Jeane is a member of our church and very active in the youth group, and one of her small sisters is a member of our Sunday School and very active also. Sometimes it looks hard for them, but still you find them very courageous in whatever they do.

Concerning the practical help, the Church has tried to give support in the following areas: spiritually, physically and some economically. Spiritually, the Church organises visits to these families in order to pray together and encourage them to read the word of God and bring them to maturity as Christians. Physically, the Church encourages these children to join others in youth groups, discussions and games at the church. Economically, sometimes we collect some money from all the members of the church and give it to such families. But still the situation has not improved a lot; there is more to be done to make a difference to such families in our community. Last time I was sharing with the youth about the future and I shed tears inside my heart because Jeane answered the group that, "Only God will determine my future, otherwise I have no dreams about my future." Generally, there is a request still to all people to adopt the heart of caring and to understand its values, for the better future in building up God's kingdom.



## CAMEROON

AVOCAM, a French acronym, is an association of women widows and orphans of Cameroon. It is an NGO which aims to assemble as many as possible unemployed, underprivileged women without any resources, in order to teach them elementary things that can help them to bring up their orphans and distract them from the torments caused by the death of their husbands.

This Association has been conceived in order to fight the crisis that goes along with general poverty, misery, idleness, starvation, disease, exclusion and exposure to sexual harassment. With the creation of this Association, we are looking for ways and means to bring back to school our orphans who are always

tempted to join the street children.

Our organisation is recognised by the Cameronian state. Our Godfather is a religious community of sisters "Sainte Cecile" and one of the sisters is the co-ordinator.

These are the reasons which led me to create the Association. When I was a headmaster of a primary school, it was not easy for parents to pay the school fees because of extreme and general poverty which aggravates every day in Africa. This situation was fatal for the widow women and unmarried girls with children. One day, I gathered some of these women that I knew very well and who play the role of both father and mother in their family.

They have to bring up, nourish, dress, cure and send their children to school with their own means. For an unemployed woman without financial activities, it is really difficult. Fortunately, they have understood that union is strength, and the number of these women increase every day. They have regular meetings to think about their situation and the future of their orphans. They also struggle to get out of the general economic crisis.

## SRI LANKA

### Caring for the elderly

Elders still occupy a very significant place in Sri Lankan society. The older a person is, the wiser that person is considered to be even if there is physical deterioration. In a traditional Sri Lankan family, the grandparents are still highly respected, and they are consulted whenever important family decisions need to be taken. All four of the major religions that co-exist in Sri Lanka – Buddhism, Hinduism, Christianity and Islam – teach respect for elders as a cardinal principle of life.

While it needs to be stressed that there are many religious and secular institutions that are working tirelessly for the care of elders, a good example would be the Anglican Diocese of Colombo. Since the 1950s and 1960s the issue of the care of the elderly has become a major concern. Retirement homes, elders' homes, and shelters were opened, the first being *Shanti Niwasa* (House of Peace), at St. Margaret's Convent, Colombo. Since then a number of other such homes have been established.

Many people who enter these homes have to do so because of the changes in the family structures in Sri Lankan society, particularly in the urbanised areas of the country. In the rural areas, elders still live with their families and are cared for by them until their lives' end. There are a number of factors as to why the situation is different in urban areas.

In May 2000 the Protection of the Rights of Elders Act, Number 9, was adopted by Parliament. This Act provides not only for the establishment of a National Council for Elders, but clear emphasis is given to the duties of children towards their aged parents, the duties of the State towards destitute elders and the entitlements that the elderly have in society where facilities, etc. are concerned. This legislation has in no small measure strengthened the hand of

those who work for a better deal for the elderly in Sri Lanka.

Seven years prior to this, a resolution of the Colombo Diocesan Council placed the care of the elderly high on the list of diocesan priorities and concerns. The Diocesan Committee for the Care of Elders has since attempted to provide the necessary impetus for enabling many to enjoy the closing years of their lives in relative comfort and peace. Bishop Swithin Fernando, one of the prime movers of diocesan action for the care of elders, made this poignant observation, "It is the boast of medical science that modern facilities have extended the life-expectancy of people much beyond what it used to be. It could be asked what use there is of extending the life of a person if in that extended period of life the necessary care for that person is not available." As he goes on to point out, there is a great need to help the elderly "live till they die" and not to allow them merely to fade and wither away in loneliness and sorrow with the cry, "I am not afraid to die; I am afraid to live."

There is much that remains to be done in Sri Lanka to enhance the care of the elderly. For example, there is need for geriatric hospitals and wards, for specially trained geriatric care-givers, and the field of geriatrics needs to be given more importance in the training schools. In Medical Education too geriatrics form no part of the curriculum. So it is in the Training of nurses and others engaged in the care of elders. This situation needs to be rectified. Another area in which we are least equipped is the care of elders in their emotional needs. Emotional upheavals in older people are not taken seriously and should be treated with more tender loving care. Compared with countries that are more affluent another area of need where elders suffer is the procurement of

medicines and other such needs. No concessions are available and the high cost of medicines in a nightmare for many.

I have no doubt that the church must provide the leadership in making the closing years of life for elders those of peace and tranquility. As for now, what is already being done needs to be continued with vigour and go from strength to strength to meet the demands of that most inescapable of realities – growing old.

In Melanesian culture, family may comprise of a father, mother, children, grandparents, aunts and uncles of both parents, the whole village, clan or the tribe. It varies from place to place but generally there is an extended family. I grew up in the village and called my father's brother "father" and my mother's sister "mother". This is still strong in the villages and there is a close relationship of the extended family members. My children call my brother "father" and my sister "mother". In this way, the children have close relationship with my brothers, sisters and the extended family in the village, clan and the tribe.

Hence, the elderly members of the family live in the same house or in their own house next to their family. In some cases, some grandchildren live with the elderly as guardian angels. They pass messages between the family members of their needs, and of course, the children learn from the elderly stories of the past, singing traditional songs, dancing or making handicrafts, etc.

Similarly, if immediate family members become single parents, they live with their parents or with older married brothers or sisters. It is an automatic family responsibility that is expected from the extended family. In the rural and urban centres this is still being practised. In the urban centres, it may be taken as an extra burden or responsibility, but in most rural centres this is part of the culture.

If there are any disabled family members, they also live with their parents or elder brothers/sisters and are looked after by everyone in the village. They are fed,

given clothing and assisted in any way to make them feel part of the family and the society.

But in some urban centres like Port Moresby, Lae and Goroka, some disabled people are seen sitting in front of the shops asking for alms. This is increasing in the urban centres, and it is very sad to see the family members of these particular disabled people, benefiting from them. I can understand that it is becoming more difficult to survive in the urban areas, especially when you are not from that particular area and only rely on your income to feed your family, pay bills and meet the hundred-and-one other needs and wants of urban living.

When it comes to orphans of the HIV/AIDS victims, there are social, health and other charity groups who are doing their best to counsel people about the disease and how to love and care for the orphans. Church representatives are also in the HIV/AIDS committees that visit hospitals or homes of the families that look after the orphans, to encourage and counsel them. Many families are fearful of taking care of the orphans because they are ignorant of the disease and how it is transmitted.

The Anglican Church of PNG has various groups such as the Mothers' Union, Youth groups, Melanesian Brotherhood companions, the Sisters of the Visitation. In the rural areas, they assist in making gardens, fetching water, firewood and taking the sick to the hospitals for medical treatments.

In the urban centres, some groups visit the sick in hospitals or at home to encourage and pray for them, but nothing

very serious is going on in terms of projects to take care of orphans/widows or single parents. Strong leadership is needed to enable and motivate them to set up projects to reach out to others.

The Sisters of the Visitation in Popondetta Diocese have a "Family Apostolate", where they take in women from domestic violence or separation, for counselling and encouragement, spiritual and physical.

Furthermore, the Anglicare Project in the Port Moresby Diocese, which started in 1999, is aimed at conducting HIV/AIDS and other sexually-transmitted diseases awareness programmes, programmes on family life (domestic violence) and gender issues. It is a project to provide education to anyone on these issues and to give counselling if needed. The project was also intended to offload the burden that the social and health workers face in dealing with the large numbers of people experiencing these problems.

Fortunately, the AUSAID Project has a construction underway to extend this aspect of the programme. When completed, this will be used as a centre to expand to the other centres in the country. It is hoped that this may be a venue for the training of trainers for the other agents in basic AIDS counselling skills and others as needed.

In conclusion, Papua New Guineans should be encouraged to hold onto the culture and look after the sick, elderly people, single parents, orphans and the disabled members of the family. It is not the Melanesian culture to leave elderly parents/relatives, disabled and the sick in a hospital or centre for the government to look after. As most people live in the rural areas, they take care of them as they are obligated to do so. Nevertheless, good research is required to determine what people think about caring for the same.

It is a burden in the urban areas as resources are scarce, but in the rural areas, there is much land to be cultivated which can easily feed everyone. The only people that go hungry are those who are too lazy to dirty their hands and rely on relatives to feed them. Schools and health centres in most rural areas are much needed. People have to travel far away to get medical assistance, and at times they let the sick suffer in the villages.

## INDIA

Today, Rekha is drained of all emotions. Is it because she has offered them like fresh flowers, soft, silky, sweet-scented at the altar of her family happiness – only to be discarded, disowned when the worship is over?

The day following her 20th birthday, Papa was carried home by his friends, a robust man turned disabled after a stroke. The stroke shattered her dream, made her a clerk in the same hospital where she was dreaming to be a doctor. On the gain side she has her two sisters married, happily living their lives, ever grateful to her. The fourth child of the family, a son – for whose arrival her parents have gone on pilgrimage to Badrinath, Rudrapryag in Himalayas, incurring heavy debts in arranging "Yagnyas" to coax Goddess

Parvati to bless them with a son – is now an unemployed young man doing odd jobs to collect his pocket money. He has no time to sit with his paralysed father, no intention of helping mother in daily chores, as those are women's jobs. Rekha has never felt disturbed by these small matters of her family. Her brown twinkling eyes never have shown the tiredness her body felt when commuting in local trains with human mass, jostling for space to keep at least one foot on the ground while one hand grips the overhead rod and the other tries to safeguard her bag. That is the usual thing to do for thousands of working women in Calcutta. So also Rekha does!

But an incident last night opened her eyes, shattered her pride in her devoted

sacrifice. Before leaving work, she had a phone call to say that her friend lay unconscious on the road. Rekha got her to a nursing home, but could let no-one know the situation, as rain had put all the telephones out of action. Dealing with the police and the wounded girl's family, who eventually arrived, took all night. When she arrived home in the morning she was greeted with accusing eyes. The neighbours – and her family – thought she had stayed with a man or eloped. The incident exposed the ugly gnawing claws of the lower-middle class propriety of her social status. She felt betrayed.

## AUSTRALIA

As I write this article I am conscious that there are many people living in countries without the practical and financial support that is available in Australia.

Thirty-three years ago, my husband, two little boys and myself welcomed a tiny baby girl into the world.

Katie has multiple disabilities, including intractable epilepsy.

What has this meant over the years? Laughter, tears, frustration, screams, seizures, joy, love, pain, a curtailed lifestyle, grief.

Grief for the "hidden" person behind the damaged brain.

Damaged for the daughter that might have been.

Tears of pain for us and for our daughter. Katie has had major brain surgery twice.

As parents we will never forget the agony of those days and the years following.

Nor do we forget how brave Katie is, she doesn't flinch at blood tests, has a bruised and scarred body from being thrown through a window, thrown across concrete as massive seizures overtook her.

She manages, and today with modern medications is greatly improved.

Katie writes and those who take the time to read what she is really saying get to know Katie, who is bright, attractive, mobile and well-spoken.

When Katie was in her twenties we commenced preparing her to live in the community, she was ready to move out and be more independent. It wasn't to be, funding was not granted.

My husband and I changed all our retirement plans and today the three of us live together.

The burden is "Who will care for my child when I am no longer here?"

I have finally made a "drop dead" book.

A book of information that previously has been in my head and will be needed in case I "drop dead". (This idea came from a fellow parent.)

An Anglican group "Crosslinks" provides the opportunity for spiritual development for people with an intellectual disability. Small groups, staffed by volunteers, many of them MU members, meet together in a local parish. A teaching and worship programme is held, including a shared meal.

With Katie, our family has had the opportunity to explore places where we might never have gone: -

- Meeting parents and siblings of disabled children.
- Knowing which friends accept all the members of our family.
- Enabling our sons, their friends and now our grandchildren learn about accepting people as they are, that we all have abilities, some people are just different.

The aspect that is different in our lives is that in retirement, as in earlier years, my husband and I are not free to simply pursue our own activities. Always it is: where does Katie fit in?

## AUSTRALIA

### Kingsdene Special School.

One in 12 children in Australia has a disability. For over 25 years, ANGLICARE's Kingsdene Special School has been on the forefront of disability education and care. Kingsdene combines a school and residential programme for children aged between 9 and 18 with a moderate to severe intellectual disability.

The Principal of Kingsdene, Gloria Boyd, has seen 20 of these years. Increasingly, enquiries about Kingsdene are from parents who have children with high support needs. These range from children with autism and unpredictable aggressive behaviour, to children with cerebral palsy who require wheelchairs and those who have uncontrolled epilepsy, behavioural disturbances and sensory impairment.

"It's not an easy job or always a rewarding one. The work we do is very humbling," Gloria says.

"Being able to meet the children's changing needs is becoming increasingly difficult. We need more resources and more than our own wisdom and strength. I truly believe that we are here to do God's work, as He helps us to understand each child's complex behaviours. Each child requires understanding and support to cope with everyday routines and situations. That's why our trust is always in Him."

When Kingsdene began, it was the first school of its kind in the country. It is still one of only two schools in Sydney to provide five-day-a-week residential care and special education. *It is still the only refuge for many families.*

Its success is written in the hearts of all the generous supporters along the way. And it is written in the individual life histories of each and every child.

Lucy, for instance, came to Kingsdene when she was 12, confused and afraid. For Lucy, who suffers from autism, the world was a noisy, chaotic place. The hydrotherapy pool gave her immediate comfort – the warmth and calm of the water soothed her anxious mind. She gained work experience with a local business through the long-running employment programme. With individual tutoring, she learnt the practical life skills essential for her growth into a young adult. Her parents were overjoyed – for the first time their special daughter was happy, truly happy. And Kingsdene's support meant her parents could give more time to their other children.

Lucy is one of many. These are children who need help with every daily task. But these are children whose achievements are second to none. The school has always reached out to the most needy of children. But never before has it needed more support. Because never before have the students' disabilities been more severe. Most of Kingsdene's current students have no verbal communication skills at all.

## ENGLAND

### The Children's Society Young Carers Initiative

It's Monday morning, and Helen's schoolfriends chatter excitedly as they swap their news of boyfriends and parties. But when they ask 15-year-old Helen what she did at the weekend, she invariably answers, "I looked after my brother."

Helen's younger brother has severe epilepsy and has to be watched constantly. But her mother is diabetic and her father has a spinal disability. So it is Helen's responsibility.

"I try to do things with friends, but it's difficult," she says "Recently, my friend wanted me to go swimming. I said I couldn't because I had to look after my brother and she said "Why? Can't you leave him on his own?" She didn't understand. I can't even go to the park without him."

Helen is one of an estimated 51,000 young people (aged under 18) in the UK who routinely care for a relative who is ill or disabled. Her responsibilities have forced her to grow up fast and set her apart socially from her peers. And her education is affected too: she can't always do her homework, and often comes to school distressed if her brother has had a fit.

While her schoolfriends are out playing, young carers are doing the weekly shop, cleaning the house or cooking supper. While their friends are watching TV, they may be putting their siblings to bed. It's very difficult to go out and impossible to have friends round. As a result, many feel very isolated. Disturbingly, 71% report being bullied at school.

Often, Helen's only chance to get out is on the evening she goes to the Young Carers' Group. Here, for once, she doesn't feel different. The young people in the group look after family members with a wide range of conditions, including physical disabilities, long-term illnesses, mental ill health and illnesses relating to

alcohol or drug misuse.

Until recently, young carers have been a hidden group. Often, parents have been afraid to ask for help in case their children are taken into care, or have not wanted strangers in their home. Some families have not realised that they are entitled to have their needs assessed. As a result, young carers have been blamed or even excluded if they miss school or fall behind, and some of their teachers do not understand the problem at home. This in turn damages their future prospects. But thankfully, this climate of secrecy is changing and projects to help are being developed.

The Department of Health has funded The Children's Society to develop a National Young Carers initiative for England. Its two key aims are to consult with young carers and to share information about policy and practice.

In partnership with the YMCA (Young Men's Christian Association), The Children's Society holds an annual young carers festival. Last year, over 1,000 young carers from all over the UK camped for the weekend at Fairthorne Manor and had the opportunity to take part in activities such as abseiling, canoeing, archery and art and drama workshops. They also took part in consultations, telling us what they and their families needed. After the festival, a small group was invited to go to the House of Lords and make a presentation to the All Party Parliamentary Group for Children. They have been asked to return and report again after this year's festival and let the Parliamentary Group know what has improved.

## Dementia

### A case history

Muriel was diagnosed with dementia 18 months ago and while her husband has a break she has come to stay with her daughter Barbara.

Barbara says: "I can tell Mum is missing Dad. She doesn't say but she always wets the bed the first two days she stays. My task is easier than Dad's because I can give her a good holiday and then hand her back. Dad has her all the time and has had to get a burglar alarm to alert him to the fact that Mum is trying to 'break out' in the middle of the night to go shopping because she's lost all sense of time.

I do have difficulty balancing Mum's needs against those of my own daughter. Mum shouted out a string of words which meant nothing and then laughed. It upset Kelly to see her Gran like that, especially when Mum said she was looking for her Dad – when he died 30 years ago. Strangely she now gives me lots of hugs and kisses – I don't remember her being very affectionate when we were young. I know that she is still my Mum inside but it is difficult to be patient when she does strange things like collecting up all the towels in the house or hiding things in unusual places."

### Feelings experienced by carers

Being with a relative who is very confused may well make you:

**angry** when they are difficult

**disgusted** when they do something they would never have done before

**guilty** because you sometimes lose your temper or fail to respond

**lonely** because you feel no-one else understands what it is like

**afraid** about what may lie ahead

**envious** of others who are not going through your experience

**despair** that the good times will never come back.

### Spiritual well-being of people with dementia

Spiritual well-being is a basic human need. It is an important but greatly neglected dimension in the lives of people with dementia. This is a condition in which the cells of the brain die more quickly than in normal ageing. This leads to a general decline in a person's abilities. It produces loss of memory, confusion, odd behaviour and personality changes. It is a complex and perplexing condition whose causes are not yet understood. There are two main types of dementia. In Alzheimer's Disease, changes take place in the brain leading to the death of cells and a gradual and slow decline. In multi-infarct dementia, mini strokes occur which destroy small areas of cells and here the illness progresses in a step-like manner.

In all about 600,000 people in the UK have dementia and many more live with its consequences as relatives, friends or carers. As the population ages, the numbers will increase further to an estimated 855,000 in the year 2020. This is because it is a disease mainly of older age – whilst only 1 in 20 people aged 65 has dementia by the age of 80 this figure increases to 1 in 5. For many years dementia was regarded as a medical condition for which nothing could be done. Those who suffered from dementia were often contained in hospitals, shut away from society.

It was to counter this view that the Christian Council on Ageing Dementia Group was founded in 1990. We are a multi-disciplinary ecumenical group and believe passionately that to provide good quality person-centred care, the uniqueness of each individual with dementia must be considered. Care staff, relatives and the general public have some appreciation of physical, mental and emotional needs but spiritual needs are still neglected, often through lack of understanding and access to training.

In the words of a carer, "there is a big gap between those who know about dementia and those who actually care for the people who have the disease. There needs to be more communication, particularly with the spouse who may have known and bonded with someone for 50 years or more and suddenly has to care for a stranger who remembers nothing of those years. The churches and the schools could do more if they knew it needed doing. We all need to understand that a person is still a person even when a part of the brain has ceased to work

properly. If we are frightened by their strangeness, how much more must it be frightening for them?"

Our Group aims to bridge this gap by focusing on the spiritual needs of people with dementia. By spirituality we mean the way in which an individual responds to and makes sense of the raw experience of life – for instance moments of delight and sorrow, understanding and bewilderment, hope and despair. These can be interpreted within or without a religious framework. There is a need in all of us to feel valued and affirmed, to love and be loved, to hope in something in this life and beyond, to have faith and trust in someone or something, to know peace, security and tranquillity.

The major achievement of our Group has been to set up and manage two projects. The first three-year pilot project was set up in Newcastle in 1994. It aimed to promote a broad understanding of spirituality which could effectively include everyone. Resources produced included an award winning video *Is anyone there?* filmed in the North East, which looks with great sensitivity at the needs both of those with dementia and their carers. The second project built on the earlier work and aimed to provide help and advice to anyone responsible for providing holistic care to people with dementia – of all faiths or none. It also produces a number of useful publications, details of which can be obtained from the address below.

## NEW ZEALAND

### The 'burden of caring' for those who once cared for us...

I write not as someone who is directly 'burdened' by the responsibility of caring for others but rather as someone close to those who are.

I write as one troubled by witnessing the often overwhelming struggle confronting women who care for elderly parents, particularly those who care for the 'remaining' parent after the loss of a spouse. All of the women I know who are in this situation have assumed responsibility for parental care willingly, unselfishly and always with deep love.

Those of my friends and family who are primary parental care-givers are in my view deserving of the highest accolades. I say this not because their day-to-day responsibilities are particularly onerous (although so often they are) but rather because I recognise the extent of personal sacrifice required and always given freely. I see my friends and family members having to set aside so much of their time, energy, resources, and often their own professional work time, in order to respond immediately and appropriately to the needs of their dependent parent. I know they possess a spirit of compassion and of selflessness that I would find very difficult to match.

Now not one of those with whom I spoke would for a moment express even the tiniest measure of regret at having what they would describe as the 'privilege' rather than the 'burden' of this parental care responsibility BUT for those of us close enough to the situation who 'know' and 'see' and 'feel' some of the relationship dynamics which emerge from time to time, it is clear that there is indeed a 'burden of care' which is usually being carried with silent and yet often agonised dignity.

One of the sadnesses I often struggle with, is recognising how insular and privatised our own little worlds have become. As we individually pursue our careers, our interests and our family and community (including church) responsibilities, we find little time to consider the pressures others are facing. For most women already confronted with the ordinary demands of family life with dependent children and/or a spouse, the additional and often quite different and unpredictable demands of elderly parental care often are simply overwhelming.

The difficulty is there is often no-one to share the feelings which arise for women

in this situation. Not unexpectedly, the feelings are those of resentment at being "trapped" by the burden of responsibility, and yet at the same time feelings of extreme guilt at allowing resentment to enter in to a situation where one feels obligated, responsible and simultaneously genuinely willing to care for one's parent. Women in this situation feel unable to share their feelings of resentment for fear of being seen as selfish, abusive, uncaring, irresponsible. The irony is that the feelings of resentment are really being directed at the situation rather than at the dependent parent, and what is needed is for those of us who are closely associated with those in this situation to intervene by alleviating the stress which inevitably arises. Rather than wait to be formally invited in, we should and can as people of God, as sisters and brothers in Christ, position ourselves as pastoral caregivers to one another.

As people of God, we are charged with the task of loving one another as we are loved by God – unconditionally and always with generosity. As the "busyness" of our lives overwhelms us as individuals, as the demands of our dependent children and our spouses preoccupy us on a day-to-day basis, could we pause even just once to recognise one woman we know who is a primary caregiver for an elderly parent and could we make ourselves available to alleviate one small portion of the burden of care she will be carrying, but about which she will never ever publicly complain? In this way we might each begin to take greater and more effective pastoral responsibility for one another as neighbours, as friends, as individuals ever more readily 'becoming' as the family of Christ.

IAFN International Anglican Family Network

### NEW ADDRESS FOR IAFN OFFICE

The Family Network office has moved. The address is:  
IAFN Office, PO Box 54,  
Minehead, Somerset TA24 7WD  
ENGLAND  
Tel/Fax: (+44) (0) 1643 841 500  
E-mail: mail@iafn.org.uk

### PRAYER

LORD

You entrusted your Mother  
to an Apostle's care:  
lead us in  
*the vocation of care;*  
enable us to show  
*the grace of care;*  
strengthen us in  
*the sacrifice of care;*  
reveal to us  
*the dimensions of care;*  
help us to share  
*the burden of care;*  
we ask this in your Holy Name

Amen

Rev'd John Bradford.

### THE NEXT FAMILY NETWORK NEWSLETTER

The next Family Network newsletter will be on the theme of **Food and the Family**. We are looking for articles which cover one or more aspects of the following issues: **famine and difficulties in obtaining food; agricultural problems; family and community self-sufficiency; local experience of "fair trade;" malnutrition and other health issues; pollution and unsafe food; junk food; family meals as a focus of relationships and celebration; eating disorders.** We are looking for articles 300-500 words long and the deadline to receive them at the Network office (address below) is 30th September 2002. As always in IAFN newsletters, we want to hear both of the problems faced by families in as wide a range of countries within the Anglican Communion as possible, and also of practical projects, generally linked with Churches, which work to help.

Visit the Family Network website: [www.anglicancommunion.org/iafn/](http://www.anglicancommunion.org/iafn/)

The views of individual contributors do not necessarily reflect those of the International Anglican Family Network.