

Sixth Annual Progress Report of the College of Medicine Home Based Care Project – December 2008

Introduction

This is the sixth annual report of the College of Medicine Home Based Care Project written for private donors. It provides details of activities, financial information and outlines future plans. Financial information is also available in the annual report of the “Malawi Home Based Care Charitable Trust”, the UK based charity set up to support the project through which all money is channelled. For a copy of this report please contact kate@malawihbc.org. On behalf of everyone involved in the project, we thank you for your support.

Looking back on 2008

Funding

There are two arms to the College of Medicine Home Based Care Charitable Trust – the Bangwe arm and the Limbe arm. The funds for the Bangwe arm sought from the National AIDS Commission (NAC) have still not materialised. After months of deliberation NAC, in its wisdom, said the research was not necessary and therefore not to be funded. It appears they did not have scientists on the committee and rejected the advice of the College Research Ethics Committee which is made up of scientists and which had obtained external advice that the research was important. We have appealed and have yet to hear the results – the Executive Director sent a text message as recently as yesterday to say he will deal with this matter on Monday. We shall see. In the meantime we rely entirely on the Trust for the running costs of the nursing team in Bangwe, drugs, fuel, and phones as well as the other Trust schemes such as the orphan and patient support. The NAC is so unreliable that we have asked the Trustees to seek funds for Bangwe from other charitable foundations in the UK. This they are doing, so far without success.

In the financial year 15th May 2007 to 31st May 2008 the Trust has remitted £22,200.59 to the Trust account in Malawi. This has paid for salaries of Bangwe staff for the whole year, funds to complete the building at the health centre, fuel for transport, incidental running expenses such as phone coupons, orphan and patient support and drama group costs (see table below).



New premises at Bangwe Health Centre with staff and motorbikes

Summary of Malawi First Merchant Bank Statement		Debit	Credit	Balance
18/05/2006	Opening balance			£ 1,420.40
25/07/2007	Trust payment		£ 4,043.38	
10/10/2007	Trust payment		£ 5,078.24	
02/01/2008	Trust payment		£ 4,967.04	
29/02/2008	Trust payment		£ 3,976.95	
16/05/2008	Trust payment		£ 3,207.27	
31/05/2008	Bank interest		£ 27.71	
	Drugs	£ 72.00		
	Salaries	£ 12,194.44		
	Buildings works	£ 2,470.63		
	Cash for patient support and orphans	£ 3,142.88		
	Transport	£ 1,961.91		
	Drama group	£ 1,017.88		
	Phone costs	£ 290.00		
	Bank charges	£ 25.36		
31/05/2008	Closing balance			£ 2,485.92
	Totals	£ 21,135.06	£ 22,200.59	

As last year The Diana Princess of Wales Memorial Fund has been a good donor, allowing flexibility within budget lines and remitting promised funds on time. Each year we receive £35,000 from them which supports the Limbe arm of the home based care project. The funds also pay for drugs for Bangwe, which has relieved the Trust of the £2,500 per year burden. We send them an annual report each year which starts and finishes in August and which is available on request.

In the second half of the year The Diana Princess of Wales Memorial Fund also paid the salaries of Bangwe staff for five months. Since November, however, the Trust has had to pick up the salary bill again which now comes to £2,030 a month and running expenses of £300 a month. The hike in salaries is due to a well deserved 25% rise for all nurses in the government service and the fall in the value of sterling in respect of the Malawi Kwacha, which is tied to the US\$.

Achievements in 2008

Bangwe

The team – two nurses and three assistants have:-

- Enrolled over 200 new patients in the year in the 15 villages identified by our home based care volunteers
- Made over 1,500 follow up visits in the year, giving them the drugs, support, advice or referral they need
- Run a support group for people living with HIV/AIDS and:-
 - facilitated weekly meetings and clinic – averaging 30 attending each week out of 80 members
 - supported monthly “cook in” sessions offering nutritional and positive living advice
 - provided seed and fertilizer for the communal garden
 - purchased two treddle sewing machines and ran a three month tailoring training course for ten members. Certificates were awarded during a Christmas party given for all members of the Support and Drama Group. Another 10 will learn tailoring in January 2009
 - obtained a hand powered compressing machine as a donation from a local Trust to make bricks from waste paper as an alternative and environmentally friendly cooking fuel
 - registered the group with the National Association for People living with HIV and AIDS in Malawi (NAPHM) who provide help to mitigate the impact of HIV/AIDS in the community.
- Supported the volunteer drama group who:-
 - perform health related drama to up to a thousand people each week
 - have bought a PA system which they hire out to generate their own income
 - have done very well in a number of competitions and were asked to perform at important functions such as World AIDS day
 - have been involved in other civic projects such as the mobilisation of the community before the national census
 - have met fully the obligations of a micro-loans scheme





Apprentice mechanic Margaret with some donated tools

- Supported 20 orphans with school fees and basic school essentials. Many orphans have now been sponsored for two to three years and are reaching the end of their secondary schooling. They need and we are encouraging them to go for vocational training, which also needs financial support. One girl has completed a second year as a car mechanic apprentice; another girl has been a volunteer at the health centre four days a week for two years and starts the ten week health surveillance assistant course before Christmas, one boy is training for electrical installation and another in electronics

- Provided financial assistance to repatriate destitute families, bus fares to attend hospital appointments and food support in a crisis situation

College staff have supported the efforts of the team through:-

- Providing technical support
- Analysing results of the home based care project. The latest paper recently submitted to the International AIDS Society is available on request.



Limbe

The Limbe project mirrors the Bangwe Home Based Care scheme, with funds for two nurses, three assistants, three motorbikes, drugs, volunteer training. The catchment is larger and over 300 new patients were seen in the year. Claire has spent most of her time this year in Limbe helping to build up the quality of the service. A local Community NGO has been established and after a stormy time ending with the removal of the director has obtained funds from NAC and is beginning to play its role.

The team – two nurses and two assistants have:-

- Enrolled over 300 new patients in the year in the 19 villages identified by our home based care volunteers
- Made between 200 and 250 follow up visits each month, giving them the drugs, support, advice or referral they need
- Seen increasing numbers of patients starting on antiretroviral therapy (ART) – now 25 a month.
- Trained and supported the 72 volunteers.



Service developments

The main theme for this year has been helping the professional staff become confident and take over the full running of the scheme and consolidating the project in Limbe. Norton, the senior nurse, has taken over running both arms of the project. Christine, an experienced nurse who had previously worked with MSF has joined the team and is based in Limbe. Claire was away for quite some time in the UK and they managed well. Norton finishes his MPH soon and is writing up his dissertation which is on the response of our patients to different drug treatments.

The Bangwe team has moved up from the Salvation Army premises to the new building at Bangwe Health Centre. The building has had its teething problems – the building contractor still has not completed all the work – and vandalism is a problem, but it is used for the antiretroviral therapy (ART) clinics on set days and the team feels much more part of the Health Centre. The referral system is improving. And at least they have their own toilet, which is clean, even if the plumbing does not work!



Staff rendezvousing with volunteers

The five home based care assistants have received refresher training and now undertake many of the simple follow up visits on their own. We have asked the Ministry of Health to recognise the training course and their qualifications. We are suggesting the course is rolled out to other parts of the country.

The home based care volunteers, the drama and support groups have all been given refresher courses. They really do appreciate them and say they are never frequent or long enough.

We have continued with the pier teaching and revision classes for disadvantaged children this year – a scheme set up by the ex-VSO teacher, Johnny Millatt, who had been in Ncheu in 2002/3. End of year exam results are due out this month and it will be interesting to see if exam passes have gone up!

Looking forward to the next twelve months

All our plans are directed to working out what will happen when we leave in November 2009, which is when Cam finishes formally at the College of Medicine.

Funding support

The Diana funding for Limbe is secure until July. We will be arranging transfer of Limbe staff to either the Ministry of Health or a CHAM (mission health) institution. Until the NAC funding materialises for Bangwe we rely on the Charitable Trust. Thank goodness we have it to come to the rescue.

Some of the local volunteer groups in Bangwe have formed their own civic based organisations (CBO) like the Limbe one and are seeking funding directly from the NAC.

Claire will be spending time this coming year making robust arrangements to hand over the support schemes to appropriate local CBOs. The plan is to try to get these transferred by mid-year so that she can monitor their performance in the last six months of our stay in Malawi.

Service developments

The need for community home based care continues relentlessly. The review of the HIV prevention strategy which I did last year has been taken up by NAC and a new HIV prevention strategy is being prepared. New infections are occurring at the same rate as 15 years ago but are now often in “discordant” couples where one is HIV positive and the other negative. The prevention strategy has failed. Over a quarter of young women attending antenatal clinic in Limbe are HIV positive. The availability of ART is making a difference and for some patients, miraculous recovery, however temporary. Half our patients are already on ARTs when we first see them.

Patients now often suffer severe side effects of ART or default and need to be encouraged to continue treatment. Early mortality on ART is still high – about 20% - and these patients often seek palliative care. Patients well established on ART do get break through opportunistic infections and need prompt treatment. Many know the team well and request help in good time. The clinic held in Bangwe when the support group meets on a Thursday is very busy!

We have expanded our catchment to include neighbouring villages and we will continue to do this if we have the staff and time. We now cover 170,000 people but there must be 400,000 in Blantyre and Limbe without a



Visiting a patient

similar service. The main effort, therefore, will be to help the Ministry of Health develop their own home based care services in these areas. We will offer training and support.

A couple of new anecdotes of Claire's day helps to put the whole thing into perspective.

Two recurring themes continue to haunt and inspire me. The first is the continual, unrelenting poverty. The second is people's acceptance, resilience and resourcefulness. In the face of such adversity, people are still able to smile, share a joke and remain courteous and dignified. Their manners are impeccable, their religious faith unshakeable and their survival tactics and optimism truly inspiring.

Chisomo was 18 years old. He was the only boy in an orphan headed household of 10 – 7 sisters, 2 with babies. In August, after months of undiagnosed pain, he was told he had osteosarcoma (bone cancer) in his leg. An above knee amputation was carried out but too late to stop spread to his spine. Paralysis set in and we first met him when he was terminally ill and totally dependent on an older sister for all aspects of care. The house was a falling down hovel but work had started by a local church to build another house cheek by jowl to the old one. Chisomo died 4 weeks later amongst the noise, rubble and squalor of this building site. His only pleasures in life were listening to his radio and visits from his friends. There was little we could do. We paid for the batteries and provided food support, pain relief and nursing care. He was so brave – he always greeted us with a smile and never complained. During our visits we discovered that the other older sister was paralysed from the waist down with TB of the spine, unmarried with a 4 week old baby. A younger sister was HIV positive and his other much younger siblings were suffering from malnutrition and neglect. This is not an uncommon scenario in a peri-urban community.

In contrast, Blazio's story has a happier ending! We first saw him when he had been evicted from his previous 'hovel' as the landlord thought he was going to die and therefore would no longer be able to pay rent. He was living in a tiny shack where his new landlord stored charcoal. When it rained, the water seeped in, rats scuttled across the earth floor and the only space during a visit was to perch on top of the sacks of charcoal. He was too sick to leave the house – emaciated, dirty, covered in a fungal infection and with what we guessed was advanced HIV and TB. He had no family or friends to look after him. Our first job was to get him onto TB treatment, supply food and soap and recruit our HBC volunteers to cook and care for him. He was a particularly unpleasant character (for a Malawian) and was aggressive and uncooperative, particularly to our lovely female volunteer. After three months of intensive care, we were able to get him onto antiretroviral therapy (ART) and now five months on he is able to leave the house, travel to collect his ARV's and TB drugs, wash and cook for himself, amble around the market begging for food and is actually more civil and communicative. We still help him with rent and nutritional support but soon we hope he will be fit enough to survive independently.

For those who may not know, old mobile phones (preferably Nokia) and 'ready reader' specs are much sought after. Mobiles are like gold dust, being by far the most reliable form of communication and specs are a godsend for some of our older patients can no longer read their bible and some of the tailoring group have great difficulty threading the needle. All the team and beneficiaries of the project send their grateful thanks for your continued help and interest.

Conclusions

The work would have ground to a halt this year without your support. The demand for home based care does not diminish. We hope you feel your support is being well used. The project is becoming self-reliant. The challenge this coming year is to encourage the local health services to set up home based care teams in other areas using our teams as exemplars. So, please continue to donate.

Claire and Cameron Bowie

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Christmas party for drama and support groups with presentation of tailoring course certificates