

Fife Men Project HIV/AIDS Buddy & Befriender Scheme

What does “*befriender*” mean?

This term in the field of HIV/AIDS is used to describe a person who befriends someone who is HIV+. The dictionary definition states:

Befriender: Act as friend to help, favour, be a friend.

Fife Men Project has adopted this word to encompass the word “*buddy*”, “*supporter*” and “*advocate*”. In other words a volunteer that has a role in being a friend and help to a person affected by HIV/AIDS on a personal level, whether it be on a one-to-one basis or just helping occasionally with everyday tasks. This role should not interfere with the independence or self determined choices of the service user. It is complimentary to those objectives.

The Fife Men Project has three specific areas of befriending. Firstly, “*buddies*” who are specifically allocated to service users that are HIV+. Secondly “*befriender*” who are allocated a partner, carer, family member and/or close friend of someone who cares for a person who is HIV+, whether or not they themselves have the virus. In addition there are those volunteers who support the buddies and befrienders which occasional transport, and domestic needs, the later more commonly referred to a “*service volunteers*”.

What is the role of a buddies, befriender, service volunteers?

A befriender is a friend but there are many different levels of friendship, such as in the workplace, best friends, associations or casual acquaintance. What one would tell one friend, one may not wish to share with another; it takes time to establish your friendships. It is the same within the Fife Men Project. The only difference is that you and the service user establish an agreement of your commitment, to that friendship. The agreement can be verbal or written and will be the choice of those involved.

Within the Fife Men Project there is a need to set boundaries between the befriender and service user within the agreement and the Service Co-ordinator of the project will help you establish these. A befriender should

always be aware of their own limitations and avoid created false expectations by the service user or the project. A befriender is expected to protect the service user's right to confidentiality and be non-judgemental, non pious, trustworthy, responsible and reliable. A befriender may have to take on a number of additional role, such as advocate and a link in dealing with statutory agencies including such people as social workers most probably from Fife Positive Support service, nurses from the HIV Clinic and clinical consultants in HIV and GUM services. This may occur when the service user is feeling particularly vulnerable. A befriender should be prepared for the unexpected; be flexible and strong enough to give support when it is required and be a listener when the service user needs a should to lean on.

The Fife Men Project does expect a certain commitment of a buddy, befriender and service volunteer:

The service user should be contacted by telephone/in person a minimum of once a week, unless otherwise agreed between them and that a befriender attends minimum of at least four Fife Men Project support meetings per year and an annual training day. Befrienders should remember that they are a part of a team and should learn to share the load appropriately. It must be noted that, as in any friendship, changes will happen. It is important to be honest with each other, keep the service co-ordinator informed of major changes within the friendship and be ready to renegotiate the relationship as appropriate.

In particular service users coming to terms with a positive diagnosis, is, in itself an enormous hurdle to cross, and many service users feel that a befriender is "the rocky road to no-where" and indeed, is sometimes taken by the service user to be further clarification that "time is short". At this stage, a service user might find it more appropriate to seek help from the Fife Men Project service co-ordinator who will help to waylay such fears and gradually introduce them to other support mechanisms such as financial assistance, benefit advice and practical community support.

We must remember for all of our service users there was a life before HIV/AIDS and that we are dealing with people that are living with HIV/AIDS and not simply dying from it. Most of our service users maintain a fruitful, full and rewarding lifestyle although some, for related health reasons, may not be working. We are here to assist our service users

“quality of life” and those who are directly affected by the issues surrounding HIV+ diagnosis, we are not there to “take over”.

Any difficulties that arise must be discussed with the service co-ordinator within the Fife Men Project before such events become out of control. Sometimes relationships do break down and other options for support discussed. This is neither the fault of the befriender or service user. So not feel you have failed the service user or the project. If a service user is dissatisfied, equally it may not be your fault and you have to approach such situations with honesty and keep a mutual respect. If it can not be resolved, then cancellation of your agreement may be the only option. This in the long run, may be beneficial to all concerned. Both you and the service user will have support during this time. Remember not all friendships are successful!

There may be conflicts within your befriender/service user agreement as mentioned earlier. Remember, your service user may go through mood swings, appear to be angry and you may need support at this time. Don't go it alone. There is real support in the Fife Men Project structure, and you may need this from time to time during the period you are buddying or befriending. If you are unable to cope through stress this will be of no help to you or your service user.

Sadly, in some cases, it becomes necessary to allocate a befriender to a service user at very short notice. This may be due to the service user having extreme difficulties, either psychologically, or in some cases with HIV diagnosis service users' in the early stages of the disease. This can be an extremely emotional time for the service user, the coming to terms with the need for assistance, a greater loss of independence and eventually, their life. You will not be forced to take on such a role, and we would never wish to throw anyone in the deep end. However, with the experience you gain, you may indeed have the skills and knowledge to cope with such experiences. Never underestimate yourself. Many of our service users never thought they would be able to cope with living with HIV/AIDS and yet have gained immense strength through it.

Who can be a buddy/befriender?

Provided a volunteer completed the mandatory Fife Men Project training programme and an assessment by the service co-ordinator, a member of

the management and an external assessor, anyone can come forward to consideration. However to become a buddy, only those who have first been a befriender or have experienced personal loss, can be considered. Each of us is an individual, we all have different talents to offer.

We may get along with some and not get along so well with others. However, the Fife Men Project encourages volunteers to get involved in various aspects within the organisation, for example, with administration or helping to organise fund-raising events. We also require that those who wish to be involved in the buddying/befriending service gain further experience through attending the further training courses held throughout the year.

In your initial training, especially the induction course, you will have possible members and they will have shared with you their personal experience of HIV/AIDS but some of our service users may wish to maintain their anonymity. Never under any circumstances should disclosure be made without the service users' permission.

You may meet some of our service users and not be aware of their HIV status. Many of our service users are active volunteers involved in a wide range of roles. They may share their diagnosis with you, but it is a matter of their individual choice and trust. Our service users are aware that you are joining a professional team because you care and have general concerns over issues surrounding HIV/AIDS and that you may have been touched in some way by HIV/AIDS through the loss of a friend, or indeed a loved one, so trust and confidence builds on both sides.

By way of getting to know service users through the various aspects of the Fife Men Project you may form a bond and the service user may ask the service co-ordinator whether it is possible for you to be his/her befriender. This is encouraged, as we feel this is a natural friendship development. However, the same agreement/ negotiation procedure will be implemented to clarify official befriender/service user boundaries and experience. So, all members wishing to become a befriender should complete as many training courses and activities within the Fife Men Project as possible. The experience will prepare you for a fulfilling and enjoyable role, but will also give you an insight into the extremely demanding task that lies ahead.

How does the Fife Men Project allocate volunteers?

In the first instance the service user informs the project of their needs, either by self-referral or through an advocate. We in turn ask the service user what level of involvement they expect and what you as a volunteer are prepared to commit. So, we act as negotiators between the befriender and the service user until an initial agreement is made. In some cases an advocate may approach the project to request assistance on behalf of the service user. In all cases the services co-ordinator will assess the needs and make every effort to provide suitable support, each case is based on the individual needs of the service user.

All personnel of the Fife Men Project will meet a service user at one time or another, as many service users are active volunteers. However volunteers should be aware that not all Fife Men Project volunteers or personnel require a befriender. You should be made aware that, in many cases, it is extremely traumatic for service users to come to terms with the need for a befriender and indeed, many of our service users prefer not to have such involvement until absolutely necessary. It is the individual's choice.

What are our rules and guidelines?

The Fife Men Project has certain rules for befrienders and service users alike that both parties are expected to abide by.

1. Confidentiality is of utmost importance and therefore confidence shared between the befriender and service user is on the basis of one-to-one, remains on both sides confidential, unless otherwise agreed between them.
2. Day to day care issues and conflicts regarding service users may be discussed at the befriender support meeting. This is to give the befriender space to gain support in a closed confidential environment. The same support is offered to HIV+ members through the holistic approach to service provision.
3. A befriender must contact the service user either by telephone or in person not less than once per week, unless agreed otherwise between them both. A befriender found not doing so will be asked by the services co-ordinator and then the original volunteer interview panel to explain this loss of contact continuity.

4. The Fife Men Project requests that the service user does not confide any criminal activities to their befriender as the Fife Men Project is legally bound to report serious criminal activities.
5. Befrienders should not become witnesses, executors or beneficiaries of a service users' will, other than in exceptional circumstances whereby the friendship exists prior to placement or through natural friendship development and changes in the befriender role.
6. A befriender/service user should not lend each other money or become financially involved in any joint business agreements.
7. A befriender should be non-judgemental in the work they carry out for the Fife Men Project.

At a certain stage your service user may become more ill/concerned, tempers may fray and anger may be directed toward you. This, in many cases is part of the progression of the disease and treatments that the service user may be taking. You may be faced with incontinence and vomiting, together with the service users' frustrations and fear. This may put an enormous strain on you as a befriender. Also the service user may have to spend long periods of time in hospital. Continue to negotiate with the service user his/her visiting needs and support that is depending on his/her changing clinical circumstances.

Do not prolong your visits if the service user is tired, assess the situation as it unfolds, a service user may indeed prefer longer visits rather than a short visit, he/she may well need someone to talk with and may prefer you to stay away if you cannot spend a little extra time. If you are unsure of what to do, ask the service co-ordinator. Honesty is of great importance, if you feel unable to discuss this with the service user, just ask. If we have not got the answer we will know someone who has.

- i. A befriender should never lift the service user without having the appropriate moving and handling training. The befriender with the permission of the service user should contact the relevant care professionals if extra support is needed, as we are not insured for personal injury caused by lifting load, this includes people! The befriender should not assume that other care workers know about HIV or your service users' status.

- ii. In the event of a service user passing away the befriender (buddy) should inform member of the Fife Men Project, initially the service co-ordinator, as soon as possible. If however, staff of the project are aware of a death they will in turn contact the befriender/buddy as soon as possible. The Fife Men Project considers this is our joint responsibility and duty of care. Remember there may be a number of friends within the project who might wish to pay their last respect. A befriender not providing this information will be asked to explain their reasons to the service co-ordinator and the volunteer panel.
- iii. Attempt to be aware of all eventualities. Find out such things as: details on support funding available through the project, welfare issues, medical contacts and any relevant information that may be of benefit to you and your service user. Try not to wait until problems arise as this may cause unnecessary anxiety and stress to all involved. If you are unsure ask the services co-ordinator.

Who are our service users?

Our HIV+ service users can access the service by self-referral or through another agency such as social work, clinical practitioners, partners, family etc. In the case of self-referrals and those within the prospective service users' immediate links we will ask for a letter confirming HIV+ service. This is to ensure that the service user is a bonafide and entitled to use our resources that are funded by statutory and public sources. Membership for HIV+ service users is on a permanent basis until they no longer wish to access the services. In all cases only with prior permission of the service user will we maintain post/telephone links regarding information. Service users will access our resources when it is convenient for them to do so.

What support does a buddy, befriender and service volunteer get?

Support Meetings:

These are offered to buddy/befrienders who volunteer within the Fife Men Project, there are normally bi-monthly meeting group meetings conducted by a meeting facilitator who usually would be the services co-ordinator. You would be expected to attend these meetings as regularly as possible as it is in both your and your service users interests to do so.

Part of a team:

In your role as a befriender or buddy you will be part of a team offering a professional care and support service. The service co-ordinator is the initial and continuity contact throughout your involvement with your service user and project, which also has an advisory role around such issues as referee, feedback, discipline and will inform you of any changes of policy within the Fife Men Project. As other volunteers maybe used in relation to transport, gardening, household chores etc you will need to be an effective communicator with the team.

How far do we get involved?

We have already mentioned that you will have set up an agreement with your service user and that it is between you both. Obviously things may change and as such you will occasionally renegotiate the agreement. However, small things will change slowly throughout your time as a buddy or befriender and you will not be expected to renegotiate officially every time this happens.

Many HIV+ service users live a healthy life for many years. An HIV+ service user does not have to be acutely physically or psychologically ill to be allocated support for the project service. Some HIV+ service users may rarely have bouts of clinical or psychological problems. Others have a large number of differing issues. HIV/AIDS is primarily a life-threatening condition with all that this brings in terms of clinical/psychological aspects and is extremely unpredictable. There are still many things we don't know about the disease and how it works, for example, who some people live longer than others.

As a volunteer in whatever role, it is important that you do not take over a person's life and create inter-dependence. You should not insist on washing, cleaning, housework etc. The service user may not wish this involvement, even if you feel that he/she needs help, the agreement will establish what support is required. It is vital that you remember that you have the privilege to be the guest in someone's home and as such you must respect their wishes. On the other hand do not let the service user take advantage of your good intentions and make unreasonable demands of you. If you feel that you are being abuse, discuss this as a matter of urgency with the service co-ordinator. Be sure you adhere to your agreement as it may be difficult to resolve problems without some form of

conflict and it is in everyone's interest to be aware of limitations or expectations or else you will be making a rod for your own back!

Occasionally, you may feel surplus to requirements and your service user seems quiet capable and independent. Allow him/her to be so. A service user may well tell you that you are not needed, that is okay; we all need space. But if you have not heard from him/her for some time, don't wait. Make a call or an arrangement to call around or issue an invitation for dinner or a drink. Let the service user know you are there when needed. We insist on a weekly telephone call to your service user as a minimum requirement, unless otherwise agreed.

For example, when telephoning a service user and you find they are feeling unwell, ask whether they would like you to visit, don't assume if they are unwell they don't want visitors, this may indeed mean they need a visit and are afraid to ask you directly. There may come a time when you become more increasingly involved, especially during a period of depression or illness. Adapt to change and if things seem to take a turn for the worse, call for advice and support,

What if a service user dies?

No-one can prepare for this eventuality, Each time a person dies it is difference. All volunteers, whatever their role will have been ask to attend the attachment and loss training. If you remain with a service user through the latter stages of illness you may be there when the service user passes away. In some cases you may be the only person present. This will be an emotional time and especially difficult for a partner, the family and friends. Respect this, and tread with care you have express for the service user when they are alive. If you know that time is close gain support from the project and those that have been through similar situations. Again this will have been discussed in confidence during training sessions and at our group meetings.

Due to the nature of HIV/AIDS some families and friends may only appear towards the end. There are many number of reasons for this and never assume the worst. Fear and guilt are all part and parcel of grief, even before the actual moment of death. Prior to this stage, attempt is possible, to renegotiate with the service user these particular care needs, including

what the service user need for his/her partner/family/extended family/friends.

The feeling that accompany bereavement may be difficult and will have been explored within the training and group support environment but no two situations are identical and people will react in numerous different ways. Remember why you volunteered in the first place because you care and wanted to help another human being through a seemingly unending nightmare. Be proud of that fact, it takes a lot of courage to volunteer and become a befriender or buddy, especially if it is through to the end of a service user's life and all of our members appreciate that.

In some cases a service user may not have any close relatives or friends and you may find yourself in a difficult position regarding who will take care of the funeral and personal matters in respect of the service user. In many cases the social work service/hospital will take care of the arrangements. However you may feel this is somewhat impersonal and that the service user requires our support even after death.

In this rare case the service co-ordinator will liaise with the appropriate authorities and assist in making the last arrangement as dignified as humanly possible.

If you are the only person present at the death the Fife Men Project will ensure that you are not personally responsible for any arrangements.

In all cases of a death the Fife Men Project will have an official representation at the funeral, although in certain situations this will be low-profile or discreet, as the service user/ partner/ family may not wish HIV/AIDS to be raised at such an event. There are many reasons for this and it is an individual choice and therefore not up to you, or the Fife Men Project to judge. If you do attend the funeral ensure that the wearing of a red ribbon badge/brooch has the full consent of the next of kin. Always remember the stigma concerns of the family are based on experience of prejudice and discrimination attached to HIV/AIDS. They may even fear who may find out and this may cause unnecessary anxiety. If you have strong feelings regarding this wear your emblem very discreetly.

It is vital that after the death of a service user you continue to go to the group meetings and keep in contact with the project as this will help with

the grieving process. We will ask you to take a much needed rest from your volunteer role and you will not be assigned another service user until you and we, feel that you are prepared to move on. This helps with reflection and a chance to see where you go from here. If you decide to step down from the project we will respect and understand this, but will always be on hand should you need us. If after your resting period you decide to stay on and become involved again you will always remain with experiences that will be invaluable.

Where do I go from here?

If you would like to explore the idea of befriending further and wish to become involved with the Fife Men Project you will need to contact the project service co-ordinator and arrange an informal meeting. We naturally understand that your time may be limited in respect of volunteering commitments. Even so, you have taken time and shown an interest in the idea of volunteering. We will negotiate a more formal application process and explain training that is essential for you to attend and reading references that you need to study. All volunteers are now subject to Disclosure Scotland checks and social work standards, these will also be discussed with you.

Please consider your commitment carefully and take the next step by contacting the Fife Men Project.

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