

Email Communication for Patients with a life-threatening illness

- **Major players:** There are three components: **primary person** who actually writes the messages, **vp communications** who forwards them to the group and manages the database and **group members** who receive the messages.
- **Messages:** The primary person sends a simple message to VP communications. Imagine you met a friend on the street, were asked how things were and replied with the highlights in, say, a five minute conversation. It is important that you imagine yourself in a public place. It helps focus on the facts, not let emotions run away, clarifies thinking.
- **Choice of vp communications:** This needs to be someone not in the nuclear family (parent-child). It is easier for primary person to tell story to someone not directly related. There is a strong theoretical framework for this advice. I learned this from a lecture by Dr. David S. Freeman, professor at UBC School of Social Work. His talk concerned the importance of family stories in healing multi-generational damage. In sessions, he had parents tell their stories to the therapist but in the presence of their adult children. Stories were not told directly to the children as it was too painful for both parties. A brilliant strategy and certainly crucial for our purposes here.
- **Beginnings and Endings:** Start off with the primary person's basic email list . Always err on the side of inclusion, if anyone is not up for it they can speak to vp which, again with that bit of distance, is easier than going to primary person. VP Communications should introduce him/herself to each new group member as they join with a brief explanation of how the system works and and previous messages the new member may not have received. Also canvas for more members..... 'Should you know of anyone who would like to be on list....only contact myself'. At the summing up, whatever that looks like in consultation with primary person, it is important that the vp sign off telling that this is the final communiqué. It is the first step in closure,
- **Loss of privacy:** Acceptance early on that this is probably the first casualty of a serious illness. Email simply codifies the reality of what has always been the case. Whereas the inner workings of the patient's body were formerly no one's business it now becomes a public document. It is a function of having a large and loving circle of friends and family, there is no avoiding it. In another era, updates were dispensed on the street with the inaccuracies that come from an oft-repeated story scanty on details. Now in this electronic age, it is same message going out to everyone at the same time. It can be crafted, controlled and correct and spoken in the voice of the primary person. It cuts through all innuendo, supposition, assumptions. It results in a greater sense of peace for the faithful. It is perhaps the greatest strength of the system.
- **Mechanics of setting up and maintaining:**
 - Email each group member initially with a test message which contains a short introduction.
 - Messages should come from primary person in body of email. Don't use attachments. Sometimes too confusing for members. Also anyone getting email at local library can't receive an attachment.

- Anyone with no email should be encouraged to find a friend, child or neighbor who could accept messages for them. This is not a frivolous activity and acquaintances will often put themselves out for this special need.
- Create email group as your email software instructs.
- Intermittently, send list of current members to primary person, keeping them in the picture.
- When message received, send on immediately. To avoid a huge group list being printed out, send email to yourself and blind carbon copy (BCC) to group. To bring up BCC using Outlook Express, go to 'create mail' then 'view' and click on 'all headers' Insert group there. VP may wish to add covering information that could be useful to group but remember that VP must retain transparency, you are only the messenger.
- Work on any bounce-backs. If message returned, check out reason. Phone, if necessary. Especially if a long time between messages, addresses may have changed. All minutiae is handled by vp. It is most important that vp knows reason for no communication with a group member and doesn't rest until their status is clear.
- It will happen that group members will turn to vp for small details (postal code, visiting hours) rather than bothering primary person. As vp, embrace their requests and get back asap. Leave no one hanging.

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