

Together We Are Strong

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www.facebook.com/groups/addisons.support

In the Addison's Disease Support Group, a large, world-wide support and information group through Facebook for those with any form of adrenal insufficiency, we've very sadly seen the loss of a few lives since the group was founded in early 2012. Most often, this has been from the lack of emergency injectables when a member was facing crisis. In one case, a young boy from India had complications despite his treatment. Another member coded after finally getting to an emergency room.

We have a saying in the group: "Together We Are Strong." We've proven this time and time again, showing what can be accomplished when those affected by adrenal insufficiency band together, whether through their combined efforts, information-sharing or support.

What makes the group the most rewarding, other than positively affecting the lives of those with adrenal insufficiency, has been those times when we've turned potential tragedy into triumph and saved a life that could have been lost. Since the group started, we've done this a handful of times now, including on July 19th, 2014, when a member who was in trouble posted and got a rapid response from a few of our members and two of our administrators.

A member named "Amanda" put up a post after 10:00 p.m. EST saying, "Guys I need to self-inject BP low panicking." Within five minutes, one of our newer administrators, Allison Campbell of Nashville, Tennessee, replied, followed minutes later by the inquiries of other members, asking what her blood pressure was, if she was dehydrated, and in listening to her symptoms, encouraging her to self-inject.

Amanda replied that she was scared to inject, but that her blood pressure was down to 79/42 and further explained her other symptoms, including confusion and vomiting. But she also indicated that if someone could help her with how to inject, she could do it. Allison walked Amanda through every step of using her injectable. Over several replies, Allison coached Amanda through drawing up the Solu-Cortef from the vial, how and where to inject, and ensured she was okay through every part of the process.

By 10:30 p.m., Amanda had replied back that she had injected but was vomiting, and was told to call 911 right away. A second administrator, Sheila Dahl of Westminster, Colorado, noticed the posts just after this and realized that Amanda was in the United

Kingdom, changing the instructions for her to instead call 999, the emergency number in the U.K. (we have the codes for all major countries the group covers to engage emergency services).

Fifteen minutes later, although the ambulance had been called right away, they hadn't recognized the emergent nature of the call... and Amanda began to lose consciousness. She fortunately let the group know this before being unable to respond further, and knew enough to leave her door open for the emergency services personnel.

Both Sheila and Allison tried to continue communicating with Amanda, but nearly an hour since Amanda's first post, the ambulance had not arrived.

Just as these two amazing administrators were worried that they couldn't find out if Amanda was okay, one of Amanda's friends, Jemma, came into her home and, confirming that Amanda was disoriented and not responding normally and that she couldn't get a blood pressure reading, asked for the group's help. She was told that when the ambulance arrived to, "Tell them she has adrenal insufficiency and is in life-threatening crisis," and advised Jemma to again call 999. They also instructed her to tell the ambulance crew she had injected her Solu-Cortef. Other members, reading the urgency of this post, chimed in quickly, encouraging Jemma as well, and offering their support.

Realizing that Amanda was likely in adrenal crisis, they suggested to Jemma to inject Amanda again, unless the ambulance would be arriving shortly. Jemma did give a second injection to Amanda and she finally began to respond. The ambulance came and took her to A&E ("accident and emergency," the U.K.'s equivalent to an ER). After running labs, she was given additional IV Solu-Cortef and saline. Amanda was later discharged back home and reported back to everyone that her vomiting stopped, she was able to think clearly again, and that she had gotten some sleep.

The group has six administrators spread world-wide across five time zones and another 15-member Advisory Board comprised of group members who help to keep things running well and give input on all larger decisions. We try to monitor all posts and replies for accuracy and supply information on nearly every topic related to adrenal insufficiency. There is no larger pay-off than having potentially saved a life through what the group offers. Allison jumped in and without hesitation, insistently and carefully advised and instructed Amanda and Jemma, and is to be hugely credited for Amanda's safe return home that night. With Amanda having nearly lost consciousness, it's frightening to consider what the outcome could have been without the assistance of those who were scrolling the posts and helped out. Thanks to the strength of the group's members, administrators and Advisory Board, we're heading toward our 2,000th member, growing by about a dozen more daily who we can only hope to assist with their

knowledge, care, and ultimately a positive outcome. There is no question when it comes to adrenal insufficiency, “together we are strong.”